

How to use the

ICF

A Practical Manual
for using the
International Classification of
Functioning, Disability and Health
(ICF)

Exposure draft for comment

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Contents

Preface to the ICF Practical Manual	1
Why should I read this Practical Manual?	1
What will I learn from reading this Practical Manual?	1
How is this Practical Manual organised?	2
Why was this Practical Manual written?	2
1 Getting started with the ICF	3
1.1 What is the ICF?	3
1.2 How can I use the ICF?	7
1.3 What does the ICF classify?	12
1.4 How does a classification such as the ICF relate to electronic records?	14
2 Describing functioning	15
2.1. How can I use the ICF to describe functioning?	15
2.2 What is the ICF coding structure?	18
2.3. How can I describe Body Functions and Body Structures using the ICF coding structure?	20
2.4 How can I describe Activities and Participation using the ICF?	22
2.5 How can I describe the impact of the Environment using the ICF?	25
2.6. How can I use the personal factors?	26
2.7 How can I use the ICF with existing descriptions of functioning?	27
3 Using the ICF in clinical practice and the education of health professionals	29
3.1 Can the ICF be used to enhance the training of health professionals?	29
3.2 How can the ICF be used in the education of health professionals?	31
3.3 How can I use the ICF to describe functioning in clinical practice?	34
3.4. How does the ICF relate to medical diagnosis?	41
3.5. What are the benefits of using the ICF as a common language in clinical settings?	43
3.6. How can ICF be used to evaluate the outcomes of interventions?	45
4 Using the ICF for community support services and income support	46
4.1 Why use the ICF for support services and income support?	46
4.2 How can the ICF assist service planning?	47
4.3 How can the ICF be used to establish eligibility?	48
4.4 Can the ICF support improved service integration and management?	50
4.5 Why is the ICF a useful framework to assess service quality?	51
5 Using the ICF for population-based, census or survey data	53
5.1. Can the ICF be used to inform population-based data collections?	53
5.2. What is the difference between collecting survey data and clinical data?	55
5.3. What is the starting point for using the ICF in censuses and surveys?	56

5.4. How can survey purposes be related to the ICF?	57
5.5. Can standard question sets be used?	58
5.6. What is involved in the design and testing of relevant survey questions?	60
5.7. Should analysis of data and interpretation of results also refer to the ICF?	61
5.8. What relevant question sets currently exist?	62
5.9 How can population data help examine equal opportunity outcomes?	65
6 Using ICF in education systems	66
6.1. Is the ICF useful in educational settings?	66
6.2 Can ICF help to bridge diagnostic and educational information?	67
6.3 Can the ICF be used for assessment in education?	68
6.4 Can ICF be used to understand participation in education?	69
6.5 Can ICF be used to analyse educational environments?	70
6.6 Can ICF be used to establish eligibility in education settings?	71
6.7. Can the ICF be used for goal-setting?	72
6.8. How can ICF be used to evaluate student outcomes?	73
6.9 Can ICF facilitate cooperation and integrate different perspectives?	74
7 Using the ICF for policy and program purposes	75
7.1 Why is it important to use standard disability concepts across different policy areas?	75
7.2 Why use the ICF in policy-making?	76
7.3 How can the ICF help raise awareness and identify problems?	78
7.4 Can the ICF help in the policy development process?	79
7.5 How can the ICF assist planning at systems level?	81
7.6 How can the ICF facilitate policy implementation?	82
7.7 Can the ICF help evaluate and monitor the effects of policies?	83
8 Using the ICF for advocacy and empowerment purposes	84
8.1 Can ICF be used for advocacy?	84
8.2 Can the ICF be used to measure attitudes and attitude changes?	85
8.3 Can the ICF support empowerment and independent living?	86
8.4 Can the ICF be used for peer counselling?	87
Bibliography	88
Annex 1: List of Acronyms	92
Annex 2: List of Boxes	93
Annex 3: Acknowledgments	94

Preface to the ICF Practical Manual

Why should I read this Practical Manual?

Anyone interested in learning more about use of the International Classification of Functioning, Disability and Health (ICF, WHO 2001) may benefit from reading this Practical Manual. The ICF is presently used in many different contexts and for many different purposes around the world. It can be used as a tool for statistical, research, clinical, social policy, or educational purposes and applied, not only in the health sector, but also in sectors such as insurance, social security, labour, education, economics, policy or legislation development, and the environment.

The ICF Practical Manual provides information on how to use ICF.

People interested in functioning and disability and seeking ways to apply the ICF should find the contents of this Practical Manual helpful. The Practical Manual provides a range of information on how to apply ICF in various situations. It is built on the acquired expertise, knowledge and judgement of users in their respective areas of work, and is designed to be used alongside the ICF itself, which remains the primary reference.

What will I learn from reading this Practical Manual?

The Practical Manual provides guidance on how to apply the ICF concepts and framework in practice, for example in:

- Coding and statistical use
- Clinical documentation
- Education
- Social Policy and Programmes
- Advocacy and Empowerment.

The ICF Practical Manual shares many examples of how the ICF has been used.

The Practical Manual describes **use cases** of the ICF developed since 2001, and brings together experiences from applying the classification and framework in various countries and settings since ICF was published.

The reader is expected to gain an overview of questions to consider when applying the ICF, common issues associated with ICF use, and examples of how ICF has been applied by others.

This Practical Manual assumes basic knowledge about ICF, its philosophy, and its principles, as well as the necessary skills and experiences relevant for specific applications, such as coding using ICF. The Practical Manual complements existing information, recommendations and tools, by relating applications to the ICF. It does not replace guidelines related to best practice and up-to-date methodological standards for particular user groups, such as clinicians, statisticians and educators.

How is this Practical Manual organised?

The Practical Manual is organised in a 'Question & Answer' format to help locate the information the reader is seeking.

The Practical Manual gives a range of information to support ICF use and may refer the reader to related sources.

The first section, 'Getting started with ICF', includes basic information about ICF and its usage that users should be aware of.

Similarly, the section 'Describing functioning' provides detail on the coding structure of ICF and how to use it, while pointing out common issues users may want to note when documenting functioning and disability.

Subsequent sections provide information on using ICF for a range of purposes, in various settings, and involving various stakeholders. These sections focus on specific areas of application, such as in

- clinical settings
- community support services
- income support
- population-based applications
- education systems
- policy and programme development
- advocacy.

Boxes are used throughout the Practical Manual to illustrate how the ICF has been used around the world.

The ICF Practical Manual is organized to answer commonly posed questions in a knowledge base format.

Why was this Practical Manual written?

At the time of the first edition of this Practical Manual, ICF has been in use for just over a decade. During this time various experiences have been collected, and it may be helpful to new users to be able to access and learn from these experiences.

The Practical Manual also highlights some pitfalls to avoid and provides examples of successful applications, so that knowledge of ICF use is spread as broadly as possible across a wide range of users.

The ICF Practical Manual provides real life examples of ICF implementation

Commenting on the Exposure draft

This exposure draft Manual will be reviewed and finalised in 2014. If you wish to suggest amendments to the current draft, please contact WHO staff at robinsonm@who.int. Comment received by the end of May 2014 will be considered in producing the ICF Practical Manual 2014

1 Getting started with the ICF

1.1 What is the ICF?

The International Classification of Functioning, Disability and Health (ICF) is a framework for organising and documenting information on functioning and disability (WHO 2001). It conceptualises functioning as a '**dynamic interaction** between a person's **health condition, environmental factors** and **personal factors**.'

The ICF provides a common language for disability.

ICF provides a **standard language** and **conceptual basis** for the definition and measurement of disability, and it provides classifications and codes. It integrates the major models of disability - the medical model and the social model - as a "**bio-psycho-social synthesis**". It recognises the role of environmental factors in the creation of disability, as well as the role of health conditions (Üstün et al. 2003).

Functioning and **disability** are understood as **umbrella terms** denoting the positive and negative aspects of functioning from a biological, individual and social perspective. The ICF therefore provides a multi-perspective, biopsychosocial approach which is reflected in the **multidimensional model**. Definitions and categories in the ICF are worded in **neutral language**, wherever possible, so that the classification can be used to **record both the positive and negative aspects of functioning**.

In classifying functioning and disability, there is not an explicit or implicit distinction between different health conditions. Disability is not differentiated by aetiology. ICF clarifies that we cannot, for instance, infer participation in everyday life from medical diagnosis alone. In this sense ICF is **aetiology-neutral**: if a person cannot walk or go to work it may be related to any one of a number of different health conditions. By shifting the focus from health condition to functioning, the ICF places all health conditions on an equal footing, allowing them to be compared, in terms of their related functioning, via a common framework. For instance, arthritis has been found to have very high frequency among people in Australia with a health condition and with a disability; that is, arthritis accounts for much of the disability in the population. In contrast, conditions such as autism, dementia, Down syndrome and cerebral palsy are much higher ranked in terms of the likelihood of severe disability (AIHW 2004).

The ICF covers the **entire life span**. An on-going process of updating the ICF is managed by WHO and its classifications network to enhance ICF relevance for the population at all ages.

How is the ICF used in health?

Health has been defined in the WHO Constitution as ‘a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’ (Constitution of the World Health Organization, WHO 1948).

The ICF provides a scientific, operational basis for describing, understanding and studying **health** and **health-related states**, outcomes and determinants. The health and health-related states associated with any health condition can be described using ICF.

Health conditions (i.e., diseases, disorders, injuries or related states) are classified primarily in the **International Classification of Diseases** (ICD) which provides an aetiological framework. The ICF and ICD are two complementary WHO reference classifications; both members of the WHO Family of International Classifications. ICF is not associated with specific health problems or diseases; it describes the associated functioning dimensions in multiple perspectives at body, person and social levels.

The ICF conceptualises functioning and disability **in the context of health**, and therefore does not cover circumstances that are brought about solely by socioeconomic or cultural factors. Nevertheless, if poverty results in a health condition such as malnutrition, related functioning difficulties can be described using the ICF. A health condition – whether diagnosed or not – is always understood to be present when ICF is applied.

A person's health can be operationally defined using ICF.

How is the ICF organised?

ICF organises information in two parts. Part 1 deals with functioning and disability while part 2 covers contextual factors. Each part has two components:

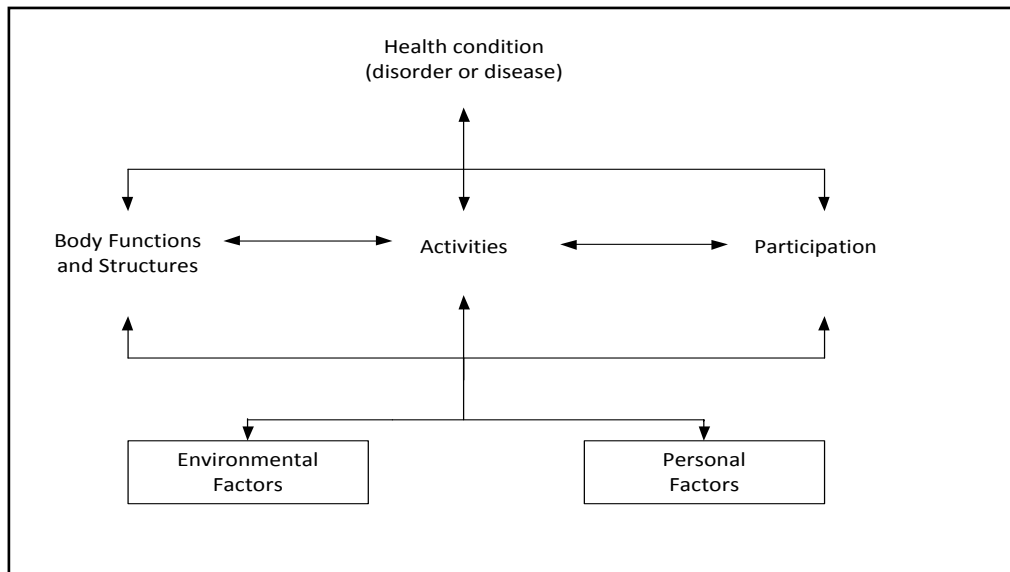
- **Functioning and Disability:**
 - Body Functions and Body Structures
 - Activities and Participation
- **Contextual Factors:**
 - Environmental Factors
 - Personal Factors.

ICF puts every person in a context:

*functioning and disability are results of the interaction between the health conditions of the **person** and their **environment**.*

The functioning of an individual in a specific domain reflects an **interaction between the health condition and the contextual: environmental and personal factors**. There is a complex, dynamic and often unpredictable relationship among these entities. The interactions work in two directions, as illustrated. To make simple linear inferences from one entity to another is incorrect; e.g. to infer overall disability from a diagnosis, activity limitations from one or more impairments, or a participation restriction from one or more limitations. It is important to collect data on these entities independently and then explore associations between them empirically.

Box 1: The ICF Model: Interaction between ICF components



WHO 2001, 18

Each ICF component consists of multiple domains, and each domain consists of categories that are the units of the classification. The ICF provides textual definitions as well as inclusion and exclusion terms for each class.

Box 2: Definitions

In the context of health:

Functioning is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Disability is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

Body functions - The physiological functions of body systems (including psychological functions).

Body structures - Anatomical parts of the body such as organs, limbs and their components.

Impairments - Problems in body function and structure such as significant deviation or loss.

Activity - The execution of a task or action by an individual.

Participation - Involvement in a life situation.

Activity limitations - Difficulties an individual may have in executing activities.

Participation restrictions - Problems an individual may experience in involvement in life situations.

Environmental factors - The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.

WHO 2001, 212-213

Box 3: Example of definition with inclusion and exclusion statements

Chapter 2 of Activities and Participation, 'General tasks and demands', is 'about general aspects of carrying out single or multiple tasks, organizing routines and handling stress. These items can be used in conjunction with more specific tasks or actions to identify the underlying features of the execution of tasks under different circumstances'. Within this chapter there is the following category:

d220 Undertaking multiple tasks

Carrying out simple or complex and coordinated actions as components of multiple, integrated and complex tasks in sequence or simultaneously.

Inclusions: undertaking multiple tasks; completing multiple tasks; undertaking multiple tasks independently and in a group

Exclusions: acquiring skills (d155); solving problems (d175); making decisions (d177); undertaking a single task (d210)

WHO 2001, 130

The functioning and disability of an individual may be recorded by selecting the appropriate category and its **corresponding code** and then adding the numbers or **qualifiers**, that specify the extent of the functioning or disability in that category, or the extent to which an environmental factor is a facilitator or a barrier. The ICF model and conceptual framework thus provide the platform for a common language and the high level structure of the classification that, in its finer details, allows for specific description and quantification. In this way, the ICF offers users the building blocks for statistical information.

1.2 How can I use the ICF?

Why should I use the ICF?

The ICF is the world standard for conceptualising and classifying functioning and disability, agreed by the World Health Assembly in 2001. It provides a freely available technical resource which is the international reference framework for health and disability information:

- The ICF supports **rights-based policies** (UN 2006, Bickenbach 2009) and provides a framework and model that assist planning and communication across government and other sectors.
- ICF provides a **common language, terms and concepts** for use by people experiencing disability, providing relevant services, or working with disability data and information. This is important because people with functioning difficulties may interact with many professionals and systems, for example health, education and social care. Processes are more efficient if all those involved are basing their approaches and communication on the common language and concepts. This is particularly the case now that some health and human services and systems provide long term services and support for the growing number of people affected by chronic conditions. A common language is essential to support this integrated care.
- ICF provides an **organised data structure** that can underpin information systems across different areas of policy and services and for policy-relevant population data. If records, research and statistics about functioning and disability are based on the ICF model and framework, they will more efficiently contribute to a coherent national and international understanding of functioning and disability and data comparable across settings and time.
- The ICF is a **multi-purpose tool** which allows for a wide range of use cases, some of which are described in this manual. It can also be viewed as meta-language to help clarify the relationship between data, information and knowledge, and to build a shared understanding and interpretation of concepts. This will be especially important if the ICF is to help to ensure consistency of application across sectors and levels of health, social and education systems.

*ICF is the **world standard** for conceptualising and classifying **functioning and disability**, agreed by the World Health Assembly in 2001*

Where can I apply the ICF?

The ICF can be used in various ways across many fields of application. This Practical Manual will illustrate some major uses in Sections 3 to 8. In brief, these are:

- **Clinical practice:** The ICF is relevant to many activities in clinical practice such as the consideration of health and functioning, setting goals, evaluating treatment outcomes, communicating with colleagues or the person involved. It provides a common language across clinical disciplines and with patients or clients. The ICF is complementary to the ICD – the global standard for classifying diseases – and, when used together, they present a full picture of the health status of an individual.
- **Support services and income support:** The ICF model and classification can support eligibility assessment, service planning, and system-based data generated by administrative processes. In particular, the focus on environmental factors makes it possible to articulate clearly whether the needs of the individual require environmental changes or the provision of personal support.
- **Population statistics:** Classification systems have been described as the building blocks of statistical information (Madden et al 2007). When population data – such as from censuses and surveys – as well as administrative and service data are based on the same concepts and frameworks, a strong, integrated national information array can be developed. This information resource can then be used to compare the numbers of people in need of various services to the number receiving them, or can indicate which areas of the social environment are most disabling for people experiencing functioning difficulties, as just two examples.
- **Education:** The same general advantages apply in the field of education as with other policy and programme areas. The ICF, as a common language, can assist with integrating perspectives from the child, the family, the school, and service systems.
- **Policy and programmes:** The ICF supports clear, conceptual thinking about disability and health related policies at a high level. The classification can further support eligibility assessment, service planning and system-based data generated by administrative processes. If the ICF is used for these purposes across policy and programme areas as well as in population statistics, then coherent, interconnected national and international data on functioning and disability can be assembled within the population. This, in turn, facilitates planning, managing, costing, resource allocation and monitoring within and across programmes.
- **Advocacy and Empowerment:** The term 'advocacy' may include both advocacy by a person on their own behalf or on behalf of someone else, as well as broad advocacy which seeks to influence system and environmental change. The ICF, as a conceptual framework for functioning and disability related to the UN Convention on the Rights of Persons with Disabilities, supports logical arguments based on international standards, and on related information and data.

The ICF Practical Manual provides examples of how ICF may be used in different ways in many different fields.

People interested in any of these uses may find it useful to reference several relevant areas of the manual. For example, people with an interest in survey design reading Section 5 may also find useful the general principles in Sections 1 and 2, information on assessment and measurement from Section 3, as well as details of other existing questionnaires such as in Section 4.

There are many other areas where ICF might be used, such as in the fields of research or training (e.g. of health professionals). While these areas of application are not discussed in detail in this Manual, it is expected that the information in this manual will still be useful and may be extrapolated to other fields of interest.

What data can be organised with the ICF?

Both quantitative and qualitative data can be organised with the ICF. The ICF provides a valuable framework for functioning and disability in **qualitative studies**, in planning a study or in organising qualitative responses. The high level articulation of components and the chapter headings may provide useful structuring for these purposes.

*ICF structure enables users to design both:
- measurement data (quantitative studies) and
- descriptive data (qualitative studies).*

The ICF framework and classification is similarly useful in planning **quantitative studies** and surveys, as its hierarchical structure also supports creating adequate data formats for different purposes at the desired level of detail (e.g. a survey question covering an entire domain vs. statistical data linked to one ICF item). ICF qualifiers can be obtained to document the extent of a problem when used in combination with any level of detail selected. Information is then ready for statistical aggregation or analysis across time and settings. More detail is given in the following sections.

Pre-existing data can be retroactively related to the ICF, as well. This may be done via a process of mapping or linking whereby the high level concepts or components of measures (e.g. assessment or outcome measures) are mapped or linked to ICF components (Cieza et al. 2005). In certain situations, this mapping may enable automatic recoding of data.

Data to be obtained from new collections can readily be based on the ICF framework and classification using **ICF based assessment instruments**. The necessary steps, along with illustration of major applications, are provided in the following sections.

How can ICF be applied ethically?

It is essential that the use of the ICF respect the rights of everyone, including people with disabilities. ICF provides ethical guidelines for the use of the ICF; these are in line with the principles of the UN Convention and require involvement of the person concerned in the design of research and data systems.

ICF respects the rights of every person and actively avoids labelling, stigmatisation and discrimination.

Annex 6 of the ICF sets out ethical guidelines for its use (Box 4).

Box 4: Ethical guidelines for the use of ICF

Respect and confidentiality

- (1) ICF should always be used so as to respect the inherent value and autonomy of individual persons.
- (2) ICF should never be used to label people or otherwise identify them solely in terms of one or more disability categories.
- (3) In clinical settings, ICF should always be used with the full knowledge, cooperation, and consent of the persons whose levels of functioning are being classified. If limitations of an individual's cognitive capacity preclude this involvement, the individual's advocate should be an active participant.
- (4) The information coded using ICF should be viewed as personal information and subject to recognized rules of confidentiality appropriate for the manner in which the data will be used

Clinical use of ICF

- (5) Wherever possible, the clinician should explain to the individual or the individual's advocate the purpose of the use of ICF and invite questions about the appropriateness of using it to classify the person's levels of functioning.
- (6) Wherever possible, the person whose level of functioning is being classified (or the person's advocate) should have the opportunity to participate, and in particular to challenge or affirm the appropriateness of the category being used and the assessment assigned.
- (7) Because the deficit being classified is a result of both a person's health condition and the physical and social context in which the person lives, ICF should be used holistically.

Social use of ICF information

- (8) ICF information should be used, to the greatest extent feasible, with the collaboration of individuals to enhance their choices and their control over their lives.
- (9) ICF information should be used towards the development of social policy and political change that seeks to enhance and support the participation of individuals.
- (10) ICF, and all information derived from its use, should not be employed to deny established rights or otherwise restrict legitimate entitlements to benefits for individuals or groups.
- (11) Individuals classed together under ICF may still differ in many ways. Laws and regulations that refer to ICF classifications should not assume more homogeneity than intended and should ensure that those whose levels of functioning are being classified are considered as individuals.

WHO 2001; 244-245

What are the main considerations in using the ICF?

There are many ways to outline the main steps in applying the ICF. Here, the process is outlined in terms of some basic questions that must be answered.

Why: Define the purpose of the undertaking: for instance, to estimate the need for services or to evaluate outcomes from interventions.

What: Identify what information is sought, relevant to the *Why*. Specify information items relating to functioning and disability and relate them to ICF components, domains and categories, including Environmental Factors. Consider all components for inclusion, and use all chapters (domains) of Activities and Participation for diverse populations.

How: What methods will be used?

- Methods may include standard survey, data system design, research, or measurement methods, but there may also be additional specific considerations relevant to functioning. Some examples of these specific considerations are included in this Practical Manual.
- Design analyses and check that planned analyses will answer the key questions and meet the main aims.
- Check whether there is existing information available or whether new information must be sought. If using existing information, plan to map to or recode the information in ICF.
- If new information is needed, identify potential sources and methods of obtaining that information. This may involve considerations of sampling, question design, or other standard questions.
- Check whether the planned collection may serve more than just your own purposes, i.e. whether there are opportunities to combine resources or collaborate across projects or sectors.
- What measurement tools will be used? How do these relate to the ICF? Mapping or linking may be required to answer this question and to enable pre-existing data to be used in ICF-compatible analyses.
- Are the methods ethical? Both the UN Convention and the ICF itself, as well as many current research procedures, require involvement of the person or persons concerned in the design of the research and data systems, and in the process of measurement or assessment (see Annex 6 of ICF, or Box 4 in this Manual).

Where and when: In what settings will the information be obtained or the measurements made? When should they be made? At what time will assessment be of most benefit to the person concerned? What repeat measurements will best inform outcomes measurement?

Who: Whose perspectives must inform what is recorded? How does the involvement of different perspectives relate to the validity of the data being recorded and its relationship to the aim? Many professionals and family members may have views on the functioning and disability of a specific individual, but the ICF recommends that the involvement of the person in question is important for validity as well as for ethical reasons. More information on all these steps is provided in Section 2 on 'describing functioning', and specific guidance on some applications may be found in other sections of the Manual.

Use of the ICF requires systematic thought and planning.

1.3 What does the ICF classify?

Does the ICF define disability?

The ICF provides definitions for functioning and disability (see Box 2 Section 1.1). However the ICF does not dictate who is 'normal' and who is 'disabled'. Using the ICF a person or a group can be identified as having 'disability' within each setting or use. What are universal and standard are the underlying concept and the dimensions of functions; the thresholds may change according to the purpose of the use case. For example, thresholds for a clinical intervention for vision may differ from those of a social support programme.

ICF provides definitions and concepts for functioning and disability which may be used to inform specific definitions in different settings.

In this sense, there are some guidelines; for instance, 'disability' for policy and research purposes may be defined, using the ICF, either a priori (e.g. defining a target group for an intervention) or post facto (e.g. selecting a subgroup by setting a threshold in population-based datasets). 'Disability' defined for specific purposes will consequently only apply for people that fit this definition. The term 'disability' may therefore refer to different characteristics in different policy sectors or countries. By using the ICF, differences in definitions can be recognised and people with disabilities who have been excluded or are underrepresented under a specific definition may be identified.

Does the ICF classify people?

ICF classifies functioning and disability, NOT the people, themselves.

The **units of ICF classification** are categories within health and health-related domains. The ICF classifies physiological (including psychological) functions, anatomical structures, actions, tasks, areas of life, and external influences. The ICF does not classify people and it is not possible to assign people to a category within the ICF.

ICF classifies functioning and disability, NOT the people, themselves.

ICF provides a framework for the description of human functioning and disability and for the documentation, organisation and analysis of this information.

To whom does the ICF apply?

The ICF is applicable to all people, to describe their functioning and level of health. As anyone may experience disability at some point in their lives, whether permanent or temporary, intermittent or continuous, ICF can be used to document the decrements in functioning domains as "disability".

ICF can be applied to anyone.

ICF was not designed, nor should it be used, to label persons with disabilities as a separate social group. The ICF is applicable to all people, irrespective of specific health conditions, in all physical, social and cultural contexts.

The **definitions** used in the ICF have **inclusions** that provide **specifications, synonyms** and **examples** that take into account cultural variation and differences across the life span. It is therefore suitable to be used in **different countries and cultures**. The ICF can be applied across the **entire life span** and is suitable for all age-groups.

Can the ICF be used for specific groups and sub-populations?

The ICF may be used both to define sub-groups and to describe the functioning or disability of specific groups, identified by age, gender, nationality or any other variable.

Particular groups can be specified by selecting certain categories in the ICF and defining threshold levels for group inclusion or exclusion. For example, it may be of interest to carry out collaborative research with people experiencing mobility limitations above an agreed level of difficulty. Other groupings may be used by service providers to define their target groups, such as individuals who require personal assistance to enable their participation in a specified area of life. In doing so users should be aware that grouping people with disabilities **can be discriminatory** if it is done as a rationale for treating people differently. Every human being, irrespective of any difference of development, functioning or health condition, is equal in dignity and rights.

ICF could be used to specify a group based on aspects of functioning and disability.

The ICF can be used to identify populations of interest for the purpose of monitoring whether all persons with disabilities are fully participating in society as required by the Convention on the Rights of Persons with Disabilities. Sub-groups, for example people with specific types of functional limitation, may need to be identified for specific monitoring purposes, e.g. whether the deaf community is given adequate recognition and support, or whether children who are blind have access to appropriate means of communication in schools. Categories or clusters of categories from ICF can be selected and used to aggregate information on functioning and disability for a group or population, such as to illustrate the higher rates of disability in older populations (e.g. WHO & World Bank 2011). Surveys and censuses may include questions on functioning and disability, thus providing information for population statistics.

1.4 How does a classification such as the ICF relate to electronic records?

Records in various formats in the health field may be based on classifications of all kinds. For instance the use of the ICD and its predecessors worldwide for hundreds of years has enabled data on life expectancy, causes of death, and health service use to be collected and used to inform health decisions in many countries. In more recent years, **population surveys and disability support services** collections have been based on the ICF (see Sections 4 and 5).

ICF may add important value to the clinical information in electronic health records to define health status.

Functional status information is increasingly recognized as an integral part of the electronic health records (EHR) architecture. The ICF as it is (with its class hierarchy with textual definitions) helps to standardize functional status information in EHRs. To ease the incorporation of ICF into EHRs, work is being undertaken to

- formalize the knowledge representation in ICF (ontology development) and
- build linkages with clinical terminologies (e.g. SNOMED-CT)

Work is also proceeding on an ontological representation of the ICF so as to facilitate its use in, or relationships to, e-Health systems.

Box 5: Ontological Model of the ICF

Since 2008 the WHO-FIC Network has been working to provide an ontological representation of the ICF, to achieve semantic interoperability for the e-Health information systems. Organizing knowledge domains in ontologies permits the creation of a common framework that allows data to be shared and reused across applications, enterprises, and communities. Additionally, the information can be processed not only manually, but also by automatic tools, including revealing possible new relationships among pieces of data (Andronache et al 2012).

There are indications that ICF, as it now is, does not show a clear ontological structure. For example, there are constructs within Activities and Participation (e.g. 'd210: undertaking multiple tasks') which can be considered as parent concepts to other constructs in the same component (e.g. 'd630 preparing meals), some constructs with similar meaning (e.g. 'b16711 expression of written language' and 'd345 writing messages') and hard to differentiate by observation are positioned in different components of the classification, with not mutually exclusive attributes. Further, attempts to map ICF constructs with SUMO (Suggested Upper Merged Ontology) or to complete a gap analysis with a clinical terminology (SNOMED CT) showed misalignment. A more stringent and logical re-definition of the ICF categories would:

- a) reduce ambiguity of concepts and improve ICF use efficacy;
- b) facilitate semantic inter-changeability among the major WHO classifications;
- c) ease the process of ICF update and maintenance.

It can be anticipated that future updates of the ICF will move it in this direction.

See: Della Mea & Simoncello 2010; Simoncello & Della Mea 2011; Della Mea & Simoncello 2012.

2 Describing functioning

2.1. How can I use the ICF to describe functioning?

Can I use the ICF to measure functioning?

The ICF framework and item pool can be used for the description and measurement of functioning. The ICF provides the building blocks of measurement and statistics in terms of concepts, definitions, categories and codes for functioning and disability as well as related environmental factors influencing them.

The ICF framework allows multiple measurement strategies. ICF categories may be measured by levels using qualifiers.

The ICF is a resource with multiple uses. This Practical Manual is a complement to the ICF and assumes that readers have a sound basic understanding of ICF. The main steps for applying the ICF are set out in Section 1.1, and these also are assumed to be understood. This section goes into further detail relevant to using these processes and undertaking these steps, following on from the more general overview in Section 1.

Should I use the codes to describe functioning?

In brief, the answer is yes, although in applying the ICF one can distinguish between (a) using the ICF model and the concepts and terms of ICF, and (b) codifying functioning information using ICF.

Functioning is described with a combination of ICF codes and ICF qualifiers.

If the ICF is used as only a conceptual model, its dimensions and domains may be used to describe functioning without using the individual ICF categories or codes. Domains can be understood as meaningful sets of body functions, actions, tasks, or area of life which capture a specific phenomenon or the experiences of an individual.

Which sources of information should I use?

The ICF is a framework for disability statistics and health information (Kostanjsek 2011) and an information system which enables the integration of data from many different sources. Information that can be organised in the ICF may come from primary sources (person experiencing disabilities) or secondary data sources (e.g. pre-existing documentation or statistics). The person experiencing one or more disabilities may provide direct information in an interview, through a questionnaire, or through other forms of self-reporting. Relevant professionals or proxies (e.g. parent, partner) may use observation, questionnaires, or measurement tools and procedures to collect information.

Information that can be organised using the ICF may come from primary or secondary data sources.

The best source of information to choose depends on the specific categories of functioning and disability that are to be captured. A professional such as a trained interviewer may have

good expertise in recording and classifying a specific area, but may not be in the best position to understand the full experience of disability as it affects other life domains. Therefore, it is important to consider the issue of who is best qualified and positioned to record and classify functioning and disability information.

Some aspects of functioning (e.g. intellectual functions) cannot be observed directly, but must be inferred through standardised testing. For other aspects, self-reported data may be the most reliable and meaningful (e.g. recreation and leisure). In some circumstances, it may be adequate to use multiple data sources for the purpose of cross-validation. Choice of data source may also depend on the age of the individual in question, and on the specific purpose for which the information is to be used. For eligibility purposes, there may be a need to establish severity levels comparable across settings independent of the specific experience of disability of one individual, while a study on social well-being might be more interested in the experience of the individual in the specific life situation.

Which methods should I use to obtain information related to ICF?

There are many different approaches that may be used to obtain information relevant to categories or domains in the ICF. For some categories in the ICF, there are specific professional standards and procedures, e.g. to measure seeing functions. For others, assessment instruments may be available that can be directly linked to contents in the ICF.

The ICF can be used to inform the collection of information using a range of methods.

Information may also be gained through observation by an experienced professional. Observations are subsequently organised into the framework of the ICF. Clinical judgement or professional reasoning is used to identify the target category and define the severity level. Observations from proxies may be obtained as well; in this case, the professional may ask additional questions to be able to establish the severity level.

Information can also be gathered through interviews either directly with the person with a disability or with a proxy. This approach is particularly useful in situations where functioning cannot be measured directly, or where the experience of disability is of greater interest than a clinical measurement. Another method may use standardised or non-standardised questionnaires or other written material provided by the person with disabilities or by a proxy. The role of the individual or individuals involved must be considered at all times.

Are qualifiers an integral part of the description of functioning?

A code is complete only when a qualifier is present, and a minimum of one qualifier must be indicated for each code. The qualifier is placed after the ICF code, separated by a decimal or + sign, and this effectively “closes” the code. The qualifier or qualifiers specify information about functioning status: the magnitude, the location and the nature of any problem.

ICF domains indicate the area of functioning; qualifiers indicate the extent of functioning or disability.

The first, common qualifier specifies the extent of a problem, whether the impairment of a body function or structure, a limitation in activities, or a restriction in participation. The first qualifier may also be used to convey information when there is no functioning problem (qualifier ‘0’), consistent with a neutral description of human functioning as advocated by ICF. For environmental factors,

the first qualifier specifies either the extent of a negative effect (the 'size' of a barrier), or of a positive effect (how strong that factor is as a facilitator); in the latter case the decimal after the code is replaced with the + sign. Important information on coding is provided in ICF itself, see Annex 2.

Box 6: The generic qualifier and an example of an ICF-code

ICF codes require the use of one or more qualifiers which denote the magnitude or severity of the problem in question. The problem refers to an impairment, limitation, restriction, or barrier when used in combination with b, s, d or e codes, respectively. Qualifiers are coded as one or more numbers after a decimal point.

xxx.0	NO problem	(none, absent, negligible, ...)	0-4%
xxx.1	MILD problem	(slight, low, ...)	5-24%
xxx.2	MODERATE problem	(medium, fair, ...)	25-49%
xxx.3	SEVERE problem	(high, extreme, ...)	50-95%
xxx.4	COMPLETE problem	(total, ...)	96-100%
xxx.8	not specified		
xxx.9	not applicable		

The letters b, s, d, and e represent the different components and are followed by a numeric code that starts with the chapter number (one digit), followed by the second level (two digits), as well as third and fourth levels (one extra digit each). For example, the following codes indicate a 'mild' problem in each case.

b2.1	Sensory functions and pain	(first-level item)
b210.1	Seeing functions	(second-level item)
b2102.1	Quality of vision	(third-level item)
b21022.1	Contrast sensitivity	(fourth-level item)

WHO 2001

What is the meaning and use of the digits 8 and 9 as qualifiers?

When the digits 8 and 9 are used as qualifiers, they have different meanings from when they are used in codes. Qualifier '8' means 'not specified', and is used when the information provided about the category is insufficient to guide the choice of an appropriate qualifier; e.g. I know there is a problem in seeing, but I do not know whether that problem is mild or severe. Qualifier '9' means 'not applicable', and is used when no specification can be given about that category. The use of the qualifier 9 will most often occur when use of the category is inappropriate for that individual, such as when coding d850 remunerative employment for a retired person, or b650 menstruation functions for a male.

The digits 8 and 9 as qualifiers mean "not specified" or "not applicable" (respectively).

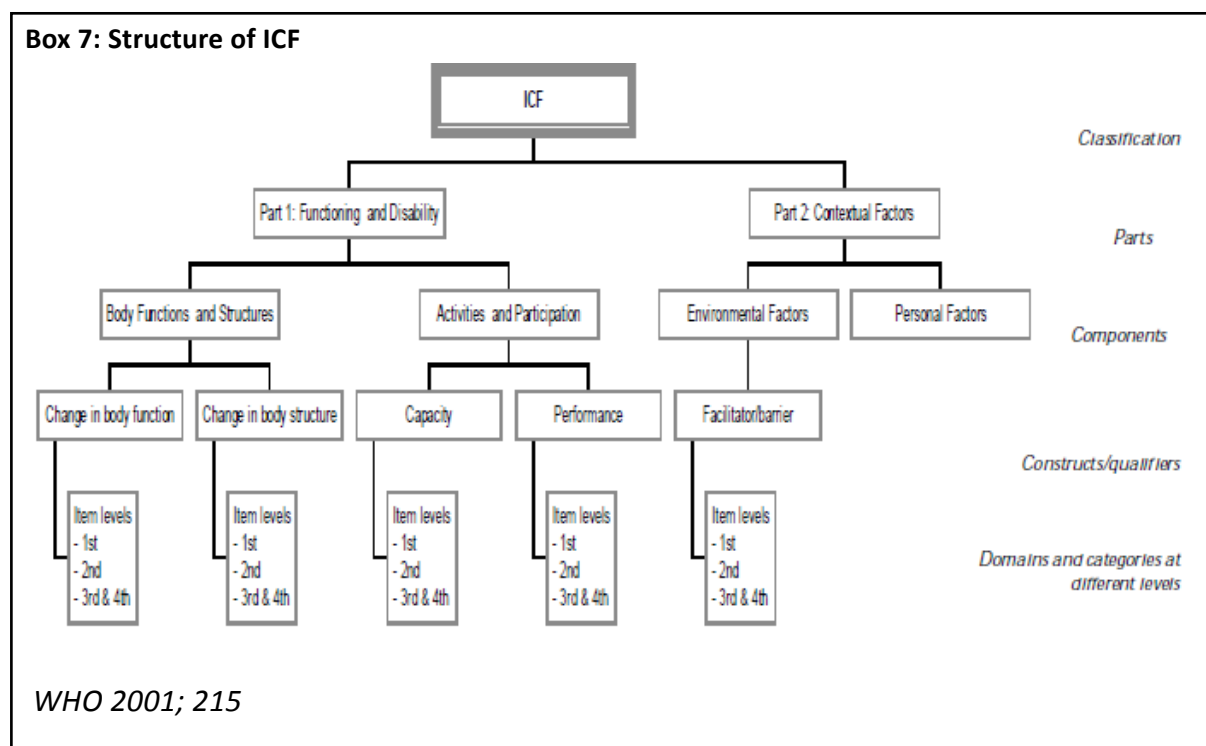
The use of qualifiers in clinical contexts is further detailed in Section 3.3.

2.2 What is the ICF coding structure?

How is the ICF organised?

The ICF is a hierarchical classification. This means that the information coded at a more granular level is preserved at the broader level, as well. Following each branch of the classification it is possible, from very general categories encompassing entire domains of functioning, to reach very detailed descriptions of specific aspects of functioning. The structure of ICF is illustrated in Box 7.

The ICF is a hierarchical classification, arranged in increasing levels of detail.



The classification is organised in two parts, each comprising two components. Part 1 - Functioning and Disability - includes Body Functions and Structures and Activities and Participation; Part 2 – Contextual Factors – incorporates Environmental Factors and Personal Factors, though Personal Factors are not yet classified in the ICF. Each component is subdivided into domains and categories at varying levels of granularity (up to four levels), each represented by a numeric code.

The prefix to an ICF code is a single letter (b, s, d, or e) representing the component in ICF where the code appears. For example, the prefix “d” represents the Activities and Participation component, although the user may choose to use the more granular, optional a (for Activities), or p (Participation), depending on their specific user needs.

After this initial letter, the number of digits which make up the code indicates the category and its level. The first digit is used for first-level categories (chapters 1 to 8 for body functions and structures, 1 to 9 for activities and participation, and 1 to 5 for environmental factors). A total of 3 digits are used for second-level categories, 4 digits for third-level and 5 digits for fourth-level categories. By reading the digits from right to left, one may easily look back from a specific code to the broader category within which it is located, moving all the way

to the domain or chapter. Conversely, when trying to select the most appropriate category to describe an aspect of functioning, one should first allocate the item to the appropriate component, then to the domain and chapter. Finally, within a given block of that chapter, one should select the category best describing that aspect of functioning with the desired level of detail.

At each level of the classification there are categories ending with either '8' or '9'. These categories may be used to signal either that the aspect of functioning is not covered by the existing definitions but is sufficiently specified to be described (- 8: other specified), or that there is an aspect present for which the information available is insufficient for further specification (- 9: not specified). Users are advised to study Annex 1 (taxonomy) and Annex 2 (coding) of the ICF for additional basics on these topics.

How can the different levels of the ICF categories be used?

There is no set rule for the level of detail to be used when using ICF, but the scope and purpose of the application should dictate the granularity required. Once information is gathered and coded at a given level of detail (e.g. with a third level code), it will always be possible to roll the information up to a broader category, but it will not be possible to capture greater specificity (e.g. fourth level) without tapping the information source again. Granularity (or level of detail) must be fit for purpose. If in doubt, a prudent approach may be to gather and code the information at the greatest specificity allowed by cost and data management capacity.

The level of detail used should be fit for purpose, and accord with the quality of information possible to collect.

2.3. How can I describe Body Functions and Body Structures using the ICF coding structure?

Aspects of physiology and anatomy are described with categories from part 1 of ICF: body functions and structures. The body is an integral part of human functioning and the biopsychosocial model considers it in interaction with other components.

The chapters on structure and function – anatomy and physiology respectively – are organized in parallel. For example, in Body Functions, functions of the genitourinary and reproductive system are in chapter 6 while the anatomy of that same system is represented in chapter 6 of Body Structures.

The molecular and cellular details of function and structure are not captured by the ICF. For example, the presence of an extra chromosome 21 in Down syndrome is not captured by ICF, but the consequences of that anomaly at the organ and function level are described.

The ICF chapters on body structure and function relate to anatomy and physiology respectively, and are organised in parallel.

What is the difference between Body Functions and Structures?

Body functions are the physiological aspects of body systems, while structures are the anatomical support. For example, sight is a function while the eye is a structure; force is a function, while muscles are structures. In some chapters, this difference may be less obvious: e.g. baldness is a problem of skin function (b850 functions of hair), not in its structure. The user should always check the definition and the inclusion and exclusion specifications attached to each category before deciding which code to use.

Body functions are the physiological aspects of body systems, while structures are the anatomical support.

The integrity in a function or a structure should not be used as an indicator that the supporting structure or function is intact, as well. Conversely, impairment in a function or structure should not be used to infer or assume impairment in a supporting structure or function. For example, a severe impairment in intellectual functions (b117.3) may be associated with an anatomically intact brain (s110.0), or an atrial defect in the heart (s41000.35) may be associated with a normal heart function (b410.0).

As all categories of body functions and structures may be applied to a single individual, simultaneously, it becomes especially important to define the areas of interest to be described or the level of detail in each domain. Again, scope and purpose should guide the user in making the most appropriate choice.

What are the qualifiers for Body Functions and Structures?

Body structures are coded with a generic qualifier, an optional second qualifier which specifies the nature of impairment, and an optional third qualifier which indicates the location, such as left or right. The second qualifier reflects the nature of the change as it is registered macroscopically. It may happen that a condition is associated with more than one type of structural change. In that case, it may be possible to select the qualifier describing the type of change most relevant to the person (the rule for doing so would need to be locally defined) or it may be possible to record all impairments related to the health condition. The third qualifier (location) should be related to the category being used (e.g. the dislocation of a lower cervical vertebra would be described with the third qualifier “6-proximal” if the code used is s7600 – vertebral column, but with the qualifier “7-distal” if the code used is s76000 – cervical column).

Body structure may have up to 3 qualifiers, relating to extent, nature and location of impairment. Body Function has one qualifier, to indicate the extent of impairment.

Impairments in body functions or structures are not always permanent or chronic. For example, pain might occur only on some days or during part of the day. In such cases, frequency, intensity and duration of the impairment should be considered as expressions of severity when coding the extent of impairment. During childhood and adolescence, impairments may also take the form of delays in the emergence of body functions during development.

In describing body functions and structures the reference point should be the expected physiology and anatomy for an average person of the same age and gender. When describing children, this might involve comparison with milestones in development achieved in the general population at a specific age.

What is the relationship between an ICF body component and an ICD code?

Some of the categories in body functions or structures may reflect a health condition as it is described and coded by the ICD. For example, b4200: increased blood pressure fully corresponds to the ICD code for hypertension). These relationships will be addressed in the current ICD revision. However, it should be kept in mind that ICF describes human functioning as a “snapshot” with none of the prognostic implications a clinical diagnosis may entail. Also, description of a specific impairment does not mean that the impairment is permanent or equate to a diagnostic conclusion.

Some ICF body categories reflect health conditions.

2.4 How can I describe Activities and Participation using the ICF?

Actions and tasks executed by individuals are defined as Activities, and involvement in life situations is defined as Participation. The chapters and categories of ICF cover all aspects of life, from basic actions such as walking and moving, to complex and socially collaborative situations such as interacting with others, or participating in school or in community life.

The Activities and Participation chapters of the ICF allow the description of all areas of life for all people.

Chapters (domains) are organized in blocks in which the categories are clustered in an ordered way, either from simpler to more complex, such as in the domain 4 (Mobility) or from general to more particular, such as in the domain 7 (Interpersonal Relationships).

The categories or blocks of activities and participation may be composed of multiple elements which relate to each other. For instance, participating in school education entails the organization of daily routine, undertaking single and multiple tasks, managing stress and demands and so on. In selecting the most appropriate set of categories to describe an activity or area of participation, one should focus on the set best representing its critical aspects and relating to the purpose of recording the information.

What are the options for delineating Activities and Participation?

ICF presents the 9 domains of activities and participation as a single list. Every action, particularly when executed in a social environment, may be considered participation, and participation always entails the execution of an action or task. Despite this relationship, the definitions of activities and participation are clearly different and distinguishing activities and participation will require careful consideration.

There are four options in Annex 3 of the ICF, with the fourth option – a single, fully overlapping list – now recommended by WHO.

When evaluating Activities and Participation, the official WHO coding style uses a single, fully overlapping list of categories. However, the user may consider any of the four options shown in ICF annex 3:

- Distinct non overlapping sets of Activities (e.g. domains 1-4) and Participation (e.g. domains 5-9)
- Partially overlapping sets (e.g. Activities domains 1-6 and Participation domains 3-9)
- All first and second level categories as Participation, and all categories at higher level as Activities
- A single fully overlapping list of categories (official WHO coding style – as mentioned above)

Recording the reasons for the choice and experience each time the ICF is used is of general interest to other users. Such recording is explicitly advised in Annex 3 where it is noted that ‘with the continued use of ICF and the generation of empirical data, evidence will

become available as to which of the above options are preferred by different users of the classification. Empirical research will also lead to a clearer operationalization of the notions of activities and participation. Data on how these notions are used in different settings, in different countries and for different purposes can be generated and will then inform further revisions to the scheme.'

What are the qualifiers for Activities and Participation?

Two qualifiers may be used to describe Activities and Participation, based on the generic qualifier and the constructs of performance and capacity. The first describes what a person does in their actual environment. The second describes what a person does in a situation in which the effect of the context is absent or made irrelevant (such as in a standardized evaluation setting). The performance of the activity or level of participation should always be observable as it reflects the actual functioning in the real life setting. However, since the performance qualifier describes the interaction between the person and the context, it may change in different environments (e.g. the functioning of an individual may change significantly when at home as compared to when at work). Options to account for this variance include coding separate profiles of performance for different environments, or making an appraisal of the performance in the most relevant setting for the purpose of the current ICF use.

Two qualifiers are described in the ICF – performance and capacity; the difference between them indicates the effect of the person’s environment.

In some instances, capacity may be easily observed by simply removing a specifically relevant environmental factor (e.g. capacity of walking could be observed for a person who uses a walking stick by taking away the stick, in a standard environment). In other situations capacity may be impossible to evaluate objectively, either because the contextual factor cannot be safely removed (e.g. a medication or an implanted medical device) or because the context is, in fact, part of the action being described (e.g. in interpersonal relationships or household activities). In these situations, capacity may be inferred by approximation, referral to previously collected data, or repeated evaluations in different settings to estimate the effect of a specific environment on the level of functioning (e.g. to note the difficulties a person has in relationships with different friends in different environments).

The combined coding of performance and capacity is a powerful technique to understand the final effect of the environment on a person, as well as allowing the user opportunities to effect changes to the environment to enhance function. 'The gap between capacity and performance reflects the difference between the impacts of current and uniform environments, and thus provides a useful guide as to what can be done to the environment of the individual to improve performance' (WHO 2001, 15).

What are the additional qualifiers for Activities and Participation?

There is a variety of optional or additional qualifiers that may be useful, including qualifiers for performance without assistance and capacity with assistance, both of which may be useful in institutional settings. The use of these additional qualifiers may allow the differential evaluation of modifications to the environment, such as assistive technology, personal assistance, or policies related to equitable access.

There are additional optional qualifiers, in different stages of development and use.

It is possible that, in the future, WHO may develop a ‘qualifier for involvement or subjective satisfaction’ for the activities and participation component (WHO 2001, 230-231). Such a qualifier (‘satisfaction with participation’) has been developed for use in Australia, to help with delineating Activities and Participation (AIHW 2006, AIHW 2003). Based on findings from ICF-based population surveys done in Japan, a distinction is made in that country between two indicators of performance of activities: ‘universal independence’ and ‘limited independence’ (Okawa et al 2008).

What is the difference between Activities and Body Functions?

Activities may relate to the interplay of multiple functions and structures. For example, speaking (d330) requires mental functions of language (b167), plus voice (b310), plus articulation (b320), all supported by the associated structures (s3). Essentials of walking (d450) include the combination of orientation (b114), balance (b235), control of voluntary movement (b760), muscle force (b730), tone (b735), mobility of joints (b710), structural support of bones (s7700), ligaments and tendons (s7701) – as well as enabling environmental factors such as well-built roads and footpaths. It is often possible to observe the specific body functions and the more complex related actions separately.

Activities relate to the whole person and may relate to multiple functions and structures.

In other cases, such as for many mental functions, the activity is the only way in which a body function may be assessed. For example, to evaluate attention functions (b140), the only available method is to observe the activity of focusing attention (d160).

2.5 How can I describe the impact of the Environment using the ICF?

What are barriers and facilitators and how do I code them?

The physical, social, and attitudinal environment in which people live influences their functioning in a substantial way. If that influence is positive, the resulting performance will be above the expected capacity; if that influence is negative, the individual will perform below his or her capacity. When an environmental factor improves performance, it is coded as a facilitator; when it lowers the level of performance, it is coded as a barrier.

The environment may have a significant effect on a person's functioning and it is essential to record the degree to which it enables or disables the person.

The socio-cultural context in which an individual lives should be taken into consideration when coding the absence of a specific environmental factor as a barrier. This may require making a judgment about what it is reasonable to expect. Is the absence of an electronic wheelchair or public transportation a barrier because it is not available in a specific rural context? In such cases, should codes in Chapters 1 (Products and Technology) and 5 (Services, Systems and Policies) be recorded as barriers? How can improvements in services be identified if these factors are not recorded as barriers?

What are the different coding options for Environmental Factors?

Environmental factors can be coded as a separate list, and in this case the weighting of their influence should be against the effect they have on the functioning of the whole person. Environmental factors can also be coded in parallel to the category on which they exert their effect. In this case, the qualifier should consider the effect that the factor has on that specific item; for example, peer attitudes may affect schooling, or technology may affect employment.

There are three options for coding Environmental factors (in Annex 2): relating to the person overall, to each ICF component, or to performance and capacity.

Environmental factors are to be coded as they relate to the individual whose situation is being described. Facilitators and barriers should be coded with reference to the influence they have on the functioning of that individual, and the qualifier should be applied to describe the extent to which an environmental factor is influencing the functioning of that individual. The perspective of the individual whose functioning is being evaluated or described represents important information and should be included in the evaluation of environmental factors wherever possible. External observers may make valuable contributions to the understanding of the effects of environmental factors and the improvements that can be made

It is not infrequent that an environmental factor acts both as a facilitator and a barrier (e.g. a drug improving some symptoms but causing adverse effects; a mother providing support for a child in one area of life but at the same time preventing the development of his autonomy in interpersonal relations; specialised transportation services that facilitate using transportation, but are a barrier as their availability is limited and they prevent public transportation services from becoming fully accessible). If the opposite effect is exerted on different aspects of functioning, it is possible to differentiate the opposing influence by attaching the environmental factor code to the affected category with the appropriate qualifier indicating its positive or negative effect (e.g. the mother facilitates self-care of the child but is a barrier to the personal interactions of that child). If the influence is observed on the same category, then one could either make an estimate of the final total effect that environmental factor has on the specific aspect of functioning, or repeating the category with a different qualifier measure.

2.6. How can I use the personal factors?

What are the personal factors?

Personal factors may include gender, age, race, lifestyles, habits, education and profession. They represent influences on functioning particular to the individual which are not represented elsewhere in ICF. An example of this is when an individual cannot get a job due to lack of qualifications, rather than any difficulty in functioning or problem in the environment. One way to include personal factors in the functioning profile is by annotation and description. Population surveys routinely gather such information as part of the survey.

Personal factors represent influences on functioning particular to the individual.

Why are personal factors not yet classified?

Personal factors are not currently classified in the ICF. This is due to the large societal and cultural variance, as well as the lack of clarity in the scope of such factors.

ICF was developed as a universal tool to describe human functioning, health and disability. Extreme variation and contextual dependency of personal factors has so far prevented a shared approach to their classification. Many elements of personal factors (e.g. economic, education and employment status) have been described and classified

There is as yet a lack of clarity about the scope of personal factors.

by other systems, such as those of international and national statistical organisations, and appropriate use of these sources may be made when including personal factors. Further, some factors that could be considered 'personal' may be already classified in ICF itself. Examples of this are b126 Temperament and personality functions or b1301 Motivation.

The development of a classification of personal factors is recognised as both a challenge and an opportunity. By including such information in data collection, an investigator may provide empirical background for the future development of personal factors in the ICF.

2.7 How can I use the ICF with existing descriptions of functioning?

How can I link the ICF to differently structured information systems?

The organisation of the ICF as a classification is based on the ICF model and follows specific taxonomic principles. Disability-related information generated independently of the ICF model and classification may or may not be easily linked to individual categories or codes on a one-to-one basis. For example, disability categories used by education systems and analysed according to the ICF model may represent:

- a health condition as represented in the ICD (e.g. Attention Deficit Hyperactivity Disorder, Autism); or
- an impairment (e.g. in attention functions or structure of the inner ear); or
- a cluster of functional problems with identification of an underlying health condition (e.g. intellectual disabilities, physical disabilities); or
- a cluster of functional problems without identification of an underlying health condition (e.g. developmental delay, learning disabilities).

The main purpose of any cross-walk should be to clarify and identify concepts and content using ICF. Cross-walks can be established to existing databases, other classifications, or disability-related nomenclatures as well as to assessment tools. Linking rules (Cieza et al 2005) are used wherever applicable.

Box 8: Information systems learn to speak ICF: the FABER solution

A web application named FABER was developed by the WHO-FIC Collaborating Centre in Italy to collect information using a multi-axial assessment framework consistent with ICF. ICF and other medical terminology systems are used to record information. The web application includes an information model and a description model. The information model contains concrete record entries. The description model provides templates for the bio-psycho-social record. The templates describe the information that may be entered, all referenced to the ICF conceptual model. Particular emphasis was placed on collecting information on environmental factors (EFs) to describe the interaction between an individual and their environment.

The FABER conceptual design was developed, and implementation of a minimum dataset for individual records was implemented, in accordance with an ad hoc biopsychosocial assessment protocol tested with more than 1,300 Italian outpatients in a national project during the period 2008-2010. FABER was populated in different steps and by different professionals who worked cooperatively. The web application releases specific outputs useful to distinguish between functioning and disability in the same functioning profile, to highlight the EFs involved, and to plan reasonable adaptations to overcome disability. A specific algorithm was designed to distinguish between positive and negative aspects of the interaction between an individual and their EFs. Two field trials were carried out in 2011 and 2012, respectively, on 400 individuals with a variety of health conditions and from different age groups. The alpha version, in Italian, was adapted to the Italian welfare system, services, and policies. An international version working in other languages and different systems is planned.

<http://www.reteclassificazioni.it>

Can the ICF help to clarify how people think about disability?

It is possible to gain insight into the way people think about disability by comparing statements and underlying premises and by asking questions and analysing textual information in the context of the ICF model, framework and classification. In some situations, the term “disability” may be used without strict understanding or awareness of the potential underlying concepts, beliefs or theories. However, ICF is based on an integration of medical and social models to provide a coherent view of different perspectives of health and disability from a biological, individual and social perspective.

ICF provides an integrated, coherent view of health and disability.

In all contexts, consideration should be given to the complexity of combining information created in different philosophical, scientific, institutional or cultural settings by individuals with different levels of personal involvement or professional interests. For example, clinical data based on information collected by a specific professional group may yield very different findings from information from a population survey based on self-reported data. Reliable knowledge upon which to take far-reaching decisions should be based on a meaningful integration of all available information.

3 Using the ICF in clinical practice and the education of health professionals

3.1 Can the ICF be used to enhance the training of health professionals?

What is the current status of health professions education?

A global independent commission on the education of health professionals for the 21st century concluded that undergraduate students are currently not adequately equipped to strengthen health systems and to address the health needs of populations (Frenk et al 2010). Healthcare advances in the last century benefit relatively few people, resulting in a widening of inequities in healthcare. This Lancet Commission report made recommendations for instructional and institutional reform of educational institutions, including strategies emphasising person-centred and community-based training to reduce this gap. This could be achieved by introducing competency-based curricula that facilitate transformative learning to equip students as agents of change. The harmonisation between the education and health systems is another crucial component that was identified. This interdependence could be strengthened through inter- and trans-professional teaching and learning (Frenk, et al., 2010).

The incorporation of the ICF framework in the education of health professionals can improve approaches to patient care and inter-professional collaboration.

The use of the ICF framework as an approach to patient care can play a strategic role in transforming the education of health professionals (Geertzen et al., 2011) and improving inter-professional collaboration (Allan, et al., 2006). This process can contribute to the strengthening of health systems and the health status of individuals.

Which health professionals should be educated to use ICF and why?

The ICF can be used in undergraduate and post-graduate training of any health professional, as well as in primary care settings and by community care workers (Snyman et al., 2012). The advantages of integrating ICF in education in this way include:

- The framework acts as a catalyst for change management as educators start modelling a holistic approach to patient care
- The traditional hierarchical structure of the team changes. Team members become equal partners in the team where their contributions are valued and an environment is created in which any appropriate team member may coordinate the management of a patient.

ICF may be applied by any health professional, and thus may serve as a foundation for inter-professional education, collaboration and practice.

ICF can be used to structure a holistic approach to management of any patient with any health condition, ensuring person-centred care. ICF does not belong to any single discipline, but is neutral. It is therefore an ideal tool to link and integrate information taught to different health professionals. The use of the ICF framework as a common approach in teaching the assessment and management of patients can result in:

- Better patient experience,
- A bio-psycho-social-spiritual approach to patient care,
- Improved health outcomes,
- The strengthening of health systems,
- Improved inter-professional education, collaboration and practice and
- Task sharing and task shifting.

The ICF framework can provide a guide for teaching public health and development of public health competencies. The environmental factors domains can provide a framework for students to collect, analyse, interpret and communicate information pertaining to: public health outcomes, social determinants of health, health promotion and disease prevention activities in collaboration with community partners, and mapping of community assets.

Does the use of ICF enhance the clinical performance of students?

There is research evidence to suggest that the use of the ICF can lead to a more holistic and comprehensive assessment and management of patients. This was found to be so when a functional model, rather than a traditional, solely diagnosis-based model, was used to assess patients with multiple sclerosis; the assessments were more comprehensive and more items requiring intervention were identified (Stallinga et al., 2012).

The use of ICF can lead to a more comprehensive approach to disability.

The introduction of the model in training physiotherapy students to manage children with developmental disorders resulted in intervention plans which demonstrated a greater awareness of the impact of contextual factors and a better understanding of participation and social interaction (Jelsma & Scott, 2011).

When medical students used the ICF framework within a primary healthcare context it enhanced transformative learning and facilitated interdependence and contributed to the strengthening of the health system (Snyman et al., 2012).

3.2 How can the ICF be used in the education of health professionals?

How can ICF inform curriculum development?

The use of the ICF framework in the development of a curriculum helps to ensure that the traditional strong focus on disease, body functions and structures is balanced by integrating activity limitations, participation restrictions and contextual factors into the curriculum. The ICF can be used to guide analysis of the needs of a community and of the health system, further informing the planning, development and coherence of curricula.

ICF use can improve education of health professionals by enhancing and balancing curriculum design.

Curriculum design can be enhanced by:

- Planning and mapping on the framework the overarching purpose of the curriculum, the specific goals, measurable outcomes, educational strategies and content. This process should include community members, students and all relevant health professions.
- Introducing ICF in a spiral fashion throughout a curriculum. The broad ICF framework can be introduced early on and more detailed information regarding codes and qualifiers, where appropriate, can gradually be added over the course of study.
- Using this framework to link content taught in different professions, disciplines and subject areas may help to break down silos that are prominent in traditional training courses (Stephenson & Richardson, 2008).
- Framing cases for problem-oriented learning with information related to the components and domains of the classification.

The importance of inter-professional education, task shifting and task sharing were key findings of the Lancet Commission (Frenk et al. 2010); all can be facilitated through the use of the ICF. Examples of how the ICF framework can be used in inter-professional education, collaboration and practice include its use to structure common patient records in comprehensive outpatient clinics (e.g. rehabilitation, psychiatry, chronic disease of lifestyle).

In joint community-based service-learning activities and research projects, the problems, research questions and outcome measures may be couched within the ICF framework.

Why use the ICF in developing clinical competence?

One of the most difficult skills that a health professional student should learn is clinical reasoning. The ICF can provide a useful framework within which to structure the assessment and management of individuals for all those involved in the patient care. The value of ICF as a teaching and learning tool for the development of clinical competence includes that:

- It provides a systematic, uniform method of gathering data across all conditions, all ages and all settings.
- Educators in each profession and discipline can use the same approach and framework, which will teach students a uniform model for assessment and treatment planning.

- Students will not compartmentalise the management of different health conditions. Instead, they will be taught to integrate information from across different disciplines (e.g. anatomy, physiology, pathology, sociology), systems (e.g. cardiovascular, musculoskeletal) and professions or specialties (e.g. surgery, public health and medicine).

(Stephenson & Richardson, 2008).

It has been found that the more familiar a student is with the ICF, the more comprehensive their assessment and management of their patients. Clinical reasoning is enhanced, allowing the student to develop a full and complete clinical and contextual profile of patients (Edwards et al., 2004).

The conceptual framework of the ICF, which emphasises that there is not a linear causal relationship between a specific health condition and the functional outcomes, is an ideal tool to encourage students to investigate and integrate the relationship between the different components.

What items of ICF should be included and at what level?

Students should be introduced to the conceptual framework of the ICF early in their training so they become familiar with the broad structure of components, interactions and domains. The student should learn how to gather all relevant data, but also how not to waste time gathering information that his not relevant to the patient’s management (Sackett et al., 1985). It may be that all health professionals should have the ability to assess functioning and health at a very high level, while different health professionals may have different requirements with regard to the use of the more granular codes, i.e. at a three or four level. The amount of information required may also depend on the functional status and health condition of the patient.

The introduction of ICF in the student’s curriculum should start early with the general framework and later proceed to the granular coding.

Can the ICF assist students in practising evidence-based healthcare?

ICF has been found useful in generating outcome-based assessments (Peterson & Rosenthal, 2005). The incorporation of ICF outcome measures into the assessment of a patient can be a valuable teaching tool, as it allows the consistent evaluation of the impact of interventions, and builds up “best practice” skills based on first-hand experience.

The ICF enables consistent evaluation of interventions, building evidence for effectiveness.

Can ICF assist in developing ethical clinical practice in students?

Health professional students should develop respect for the autonomy and dignity of their patients. ICF has eleven ethical provisions, on respect and confidentiality, clinical use of ICF and social use of ICF information (WHO 2001:244–245; Box 4 of this Manual).

The person-centred approach to assessment and management can ensure that the contextual background of each person is taken into account during interactions and when assisting in the management of health and function. This is particularly applicable in multicultural societies (Ramklass, 2009). In one study, when students applied the ICF framework, it was found that they were able to identify and take greater ownership in addressing ethical challenges related to the case (Snyman et al., 2012).

By following the ethical guidelines of the ICF the student will be guided towards a patient oriented approach respectful of cultural diversities.

3.3 How can I use the ICF to describe functioning in clinical practice?

How can I use an ICF-based patient profile?

An ICF-based functional profile may be used to complement the diagnostic information of a patient or a cohort of patients with information on functioning. This additional information provides a more robust picture of the overall health status of the individual. Such a picture is relevant and useful for all conditions, but often of particular interest in chronic conditions and non-communicable diseases. Examples of possible uses of an ICF-based patient profile include:

- Snapshot profile of a single individual to detect areas of needs, problems and strengths;
- Dynamic profile of the functional status of an individual or group to track changes, such as those due to natural history, interventions, or environmental modifications;
- Functional profile of a cohort grouped by some criteria (e.g. diagnosis, age, or gender); or
- Planning treatment or management.

What does an ICF-based patient profile focus on?

The ICF-based patient profile will always focus on the way in which the person functions at a given time, taking scope and purpose into account. Choosing a time interval and an environment that will provide a stable representation of the functioning of an individual is also advisable, for practical purposes. Examples of a time period might be one week to a month. An example of a suitable environment would be the one where the individual spends the most time, such as work or home. Setting these parameters is even more important when recording intermittent, cyclical, episodic aspects of functioning, such as sleeping, menstruation functions, driving, recreation, or participation in social events. This can also show changes over the interval, or between one environment and another.

An ICF-based patient profile focuses on the way in which the person functions at a given time.

Special focus may be given to specific aspects of functioning which are relevant to the scope of the profile. Therefore the granularity of the profile might be non-homogeneous if a specific area is of special interest and motivates the profiling. In all instances, even within the asymmetry of a profile focusing on specific chapters or domains, it will always be possible to roll up from a more granular set of codes to a higher level within the classification, such as the second level or the chapter level, to represent that profile as a homogeneous dataset.

How can ICF be used to assess functional status?

It is possible to fully represent the profile of human functioning by using the appropriate array of ICF categories and qualifiers. The ICF provides a systematic and significant ordering of all information concerning functioning. The process of producing an ICF-based profile of functioning will always imply the translation of collected information elements into ICF categories. There are two ways in which this can be operationalized:

- by translating the information gathered with existing assessment tools and instruments into the appropriate categories and qualifiers; or
- by coding the clinical observation directly in ICF categories and qualifiers.

The information gathered through clinical observation or with assessment tools can be translated into ICF categories to describe functional status.

The ICF functioning profile might result from either of these two methods or by a combination of the two. When choosing the method to be used and the level of detail (e.g. of the number and level of categories to be used), consideration should be given to the scope and the cost-benefit.

What time and resources are needed to collect this information?

The time needed to gather the information to code the profile is not dependent on ICF, but on the professional expertise of the assessors, the knowledge already available and the complexity of the assessment tools used.

Factors include granularity (i.e. the number of codes required for the profile), expertise of the coders, and the direct alignment of the assessment instrument to the ICF. For example, when using ICF-based assessment tools such as WHODAS 2.0, the translation into ICF codes is easier than when using non-ICF based tools.

Human resources are dependent on the clinical context in which the profile is performed. With multidisciplinary teams, distribution of the coding across the various professionals considerably shortens the timing and eases the workload. In other settings solo coding might be the only choice. Material resources might be limited to the ICF red book and a log book, but several experiences of computer supported profiling have been reported and tested.

The time needed to collect ICF information is dependent on the professional expertise, the knowledge available, and the complexity of the assessment tools used.

How do I choose the components and domains of interest?

To complete a functioning profile that is representative of all domains of health (see section 2), all ICF components should be considered. A prospective ICF user must first choose between a homogeneous profile that covers in equal detail all components and a profile giving specific emphasis to specific areas. After this, one must decide whether or not to limit the number of categories used - a decision often based on the scope and available resources. Finally, the user must select which codes will be used. Each selection will have different strengths and weaknesses, and there is no single strategy that suits all situations. Each user should identify the solution that best fits their scope and setting.

Each user should choose the solution that best fits the purpose, scope and setting; there is no single strategy for choosing components or domains..

Examples of tested approaches:

- **Using WHODAS 2.0 or other ICF-based assessment instruments.** Using assessment instruments that have been developed to assess functioning as captured in ICF, such as WHODAS 2.0, is the most straight-forward method.
- **Using the entire classification:** Coders select from the entire ICF the codes that are most relevant and appropriate for the person and the scope. This allows maximum specificity, but can be unwieldy or difficult to manage, while requiring a greater knowledge of coding in ICF.
- **Using a limited pre-set level:** Similar to using the entire classification, but with a limit in level of granularity allowed, such as only using to the second or third level of categories.
- **Using a pre-set short list:** This entails the pre-selection of a number of categories to be evaluated in all patients in every circumstance. There are several types of short lists:
 - **Shortlist 1 - ICF checklist:** when WHO field tested ICF, a checklist of 169 categories was prepared to be representative of the entire classification across ages, in various settings and in the context of various health conditions. The scope of the ICF checklist was to validate the classification in various field testing experiments, not specifically to be used in clinical setting. This shortlist is freely available, has been widely tested, and requires an average of 30-60 minutes to complete while providing a balanced view of all aspects of functioning. Many of the included codes may be irrelevant in a given situation, however, while some relevant to a specific situation may not be included.
 - **Shortlist 2 - Code sets for specific settings or uses:** Such checklists are developed systematically by users in that setting or application and refined for the specific use. They can be shared across settings or professions but may also be site specific. These lists can focus on relevant concerns and reduce variability between users in the identified setting, but developing such code sets can require knowledge and consensus across the field to develop prior to implementation.

- **Shortlist 3 – ICF Core sets for specific conditions:** These are checklists developed through a scientific process that includes conducting a systematic literature review, a multi-centre cross-sectional study, an expert survey, a qualitative study and an international consensus conference (Üstün 2004, Stucki 2004, Finger 2012) to best represent the typical functioning profile of persons with a specific health condition or within a specific context (e.g. vocational rehabilitation program). Examples include spinal cord injury, arthritis, diabetes, stroke, depression, and obesity. There have been further refinements to represent the functioning of individuals with a given medical diagnosis in specific stages of the clinical process, such as post-acute vs. chronic. However, co-morbidities are not specifically accounted for in the core sets and use of these can reduce the specificity of the functional profile.

How do I assess the environment of an individual?

Environmental factors can affect activities and participation as well as body functions and structures (e.g. diuretics affect b610 urination excretory functions or an intravascular stent changes a vessel lumen). While aids and equipment are by far the most common environmental factors to consider in the use of ICF, others deserve equal consideration even if they are less obvious. Examples include air quality for a person with asthma or stigma associated with a mental health diagnosis. Another example might be a clinician in a ‘standardized’ environment such as a hospital overlooking the environment as a source of variation significantly affecting functioning. In truth, the presence of personal assistance specifically aims to optimize performance despite any issue with functioning or the environment, which may erroneously result in a flat performance profile across individuals who would otherwise have significant difference in capacity or in performance without that assistance. The following are some of the points to consider when assessing the environmental impact on functioning:

When describing all environmental factors several points should be considered: usual setting, time, presence vs absence of an expected factor, source of information.

What is their performance in their usual environment? Consider the environment, such as work or home, where the individual spends the greatest amounts of time to assess the environmental impact on functioning. A clinical setting or a special care centre may not be representative of that environment. To acquire information on the relevant environment or environments, it may be necessary to perform a home visit and targeted interviews with the individual or caregivers.

Over what time period should the performance be assessed? Environmental factors or their impact may not be continuously present and relevant. For example, a personal assistant may be present only for part of a day, or a drug might provide its effect for a few hours. Therefore, it is important to use a time interval long enough to accommodate these variations.

What equipment does the individual need or use? Consider the performance with the available equipment and assistive technology. Equipment expected to be present in the context, but missing (e.g. a bed, a chair, or insulin for a person with diabetes) may be coded as a barrier. The impact of assistive technology on functioning can be noted using the additional qualifier for activity and performance (i.e., “performance without assistance”).

What personal assistance does the individual need or receive? Similar to equipment needs, in this case the use of the additional qualifier for performance will allow the separation of the modification on capacity driven by personal assistance versus that due to equipment and assistive technology.

Who is involved in providing information? Among the most relevant environmental factors may be the individuals from whom the coder obtains information (e.g. the mother for the child, the caregiver for a person with a disability). Information from the person providing assistance and support should be considered together with the information given directly by the person whenever possible, as well as with information obtained through clinical observation. The functioning profile should always start from the point of view of the individual being described representing the primary source of information. However, the functioning profile should also be as objective as possible, as a profile of functioning and health and not just the perception of health. For this reason, the final coding should blend the various sources of information in order to best approximate an impartial objective representation which nevertheless incorporates factors of importance to the person involved.

How are qualifiers used in the clinical context?

In the clinical context, the code must include at least one qualifier in order to have meaning. (See previously, Section 2.1, for general information about the use of qualifiers.)

Accounting for frequency and duration: A problem with variable frequency or duration may be qualified using the first generic qualifier. The percentage of the generic qualifier may indicate the degree of difficulty encountered or the amount of time affected (WHO 2001:22):

ICF qualifiers may be used to describe frequency, duration, or location, as well as relevant environmental factors and other information.

- _xxx.0: **no problem:** The person has no problem at any time or only very infrequently.
- _xxx.1: **mild problem:** The problem is present less than 25% of the time, with a tolerable intensity, and has only rarely occurred in the last thirty days.
- _xxx.2: **moderate problem:** The problem is present between 25% and 50% of the time, with an intensity that sometimes interferes with daily life.
- _xxx.3: **severe problem:** The problem is present between 50% and 95% of the time, with an intensity that occurs frequently and partially alters daily life.
- _xxx.4: **complete problem:** The problem is present more than 95% of the time, with an intensity that totally alters daily life.

Using the third qualifier in Body Structure: The third qualifier for body structure identifies the location of the problem. When there is no possible ambiguity about the location of the problem (e.g. hepatic steatosis (fatty infiltration) involving the whole liver: s560.x7; or cranium size exceeding normal dimensions: s7100.x4) this qualifier can be omitted.

Using qualifiers 8 and 9: The meaning of qualifiers 8 and 9 is explained in Section 2.1

- The qualifier 8 (not specified) may be chosen whenever it is known that a problem is present but it cannot be quantified nor specified in terms of its nature or location. The information that a problem is present may be by itself relevant and sufficient, whatever the magnitude of that problem. Moreover, it may signal the need for further assessment to allow more precise quantification.
- The qualifier 9 (not applicable) may be used when it is not possible to even indicate whether a problem is present or not. This may happen because of lack of information, or because the information is not retrievable. There may be categories in checklists or other fixed lists of codes that are not applicable to a specific person (e.g. b6601.9, b6602.9, b6603.9: functions related to pregnancy, childbirth and lactation for a male). Qualifier 9 may indicate an Activity not routinely performed by the person when there is no way of knowing whether that person has the capacity to do it (e.g. d630.99 for a person who never tried to make up a meal).

Various Options for Activities and Participation in the clinical context: The qualifiers for Activities and Participation are explained in “describing functioning” (Section 2). In the clinical context, the use of third or fourth qualifiers (capacity with assistance and performance without assistance) may allow the precise description of the degree of independence an individual has in performing a task with the help of equipment, which may constitute a specific goal of treatment or a relevant outcome (e.g. achieving self-catheterization without supervision or personal help for a patient with neurologic bladder).

Options for Environmental Factors used in the clinical context: The options for coding environmental factors are explained in “describing functioning” (Section 2). The cost-benefit for the different options should be evaluated when using ICF in the clinical context. For example, the environmental impact on a specific category improves specificity, such as with body functions and the effect of drugs on the targeted function (e.g. b420 blood pressure functions are modulated by anti-hypertensive medications). However, there may be duplication in Environmental Factor codes affecting multiple aspects of functioning (e.g. the support of the immediate family for a child are quite pervasive and extend to most aspects of A&P).

Conversely, the use of a separate “environmental factor” list of categories may be more artificial and require the coder to balance the effect of that factor on the whole profile of functioning, requiring a degree of approximation.

Quantifying the impact of Environmental Factors: Two options may be followed:

- Consider the impact as the amount of change brought by the environmental factor to the functioning of the individual. An Environmental factor cannot be considered a modulating factor if it is not changing the functioning of that individual.
- Reference the difference between performance and capacity observed for the categories on which the specific environmental factor is acting.

How do ICF qualifiers relate to existing tools?

Assessment tools can be used in clinical practice to measure many aspects of functioning, improving the objectivity of the functioning profile. However, when translating items from assessment tools into ICF categories and qualifiers, the following should be considered:

- One-to-one correspondence to single ICF categories is not always possible. For example, scales or indexes such as the Barthel index or the NIH Stroke Scale describe aspects that refer to and often overlap several domains of body functions and activities and participation. Therefore, an analysis of content correspondence should always precede any conversion.
- The grading system of the assessment tool may not correspond to the ICF qualifier scale. The full scale range of the applied tool should be compared to the 0-5 range of the first qualifier.
- The environment where the assessment has been completed may overlap with multiple environmental factors, especially when compiling assessments from different sources, settings, or assessors.

See also Section 2.7.

There is no automatic translation of scores from existing tools into ICF categories and qualifiers: a mapping analysis and scoring evaluation should always be completed.

How and why should Personal Factors be considered?

Personal factors are not codified in ICF, but may convey information important for a complete description of the functioning profile. Gender, race, ethnicity, age, social and educational background, past and current experiences and life events, character styles, behaviour patterns, and psychological assets are all personal factors that may potentially affect functioning. Personal factors relevant to the functioning of the individual may be annotated as free text any time that factor is relevant to the profile, or other standard classifications where they exist (see also Section 2).

It is important to record personal factors relevant to the functioning of the individual, either as free text or using standard classifications where they exist.

There are instances when there is a difference between performance and capacity not explained by coded environmental factors. For example a person may not be working in spite of having the capacity due to a lack of expertise matching job market requirements. In those cases, personal factors may come into play, and their description becomes important and relevant.

3.4. How does the ICF relate to medical diagnosis?

Why is ICF used together with the ICD?

In the context of various health conditions and injuries, medical diagnosis alone may not provide full conceptualization of health status and may not fully predict service needs, neither at the level of individual treatment planning nor at the level of population health policy.

Using ICF with ICD makes it possible to provide a full picture of health and functioning..

The International Classification of Diseases (ICD) provides an aetiological framework for health conditions such as diseases, disorders, or injuries. Functioning and disability associated with these health conditions, however, are classified in ICF. ICD and ICF are complementary and users are encouraged to use the two classifications together. While ICD provides a diagnosis of diseases, disorders or other health conditions, this information is enriched by additional information from ICF on functioning.

If we use ICD alone we may not have the information we need for health planning and management purposes. Therefore, using ICF with ICD makes it possible to collect data providing a full picture of health and functioning in a consistent and internationally comparable manner.

Can I use ICF in the absence of a specific health condition diagnosis?

Generally, in the absence of a health condition, ICF is not commonly used in the clinical setting. However, ICF can be used as a conceptual framework for functioning information that is applicable to personal health care, including prevention, health promotion, and the improvement of participation by removing or mitigating societal hindrances and encouraging the provision of social supports. The ICF can be used (even before a diagnosis is identified) and likewise to describe the functioning of a child, as a means to describe developmental delays.

ICF can be used as a conceptual framework for information that is applicable to personal health.

Can ICF be used in casemix groupers and Function Related Groups (FRG)?

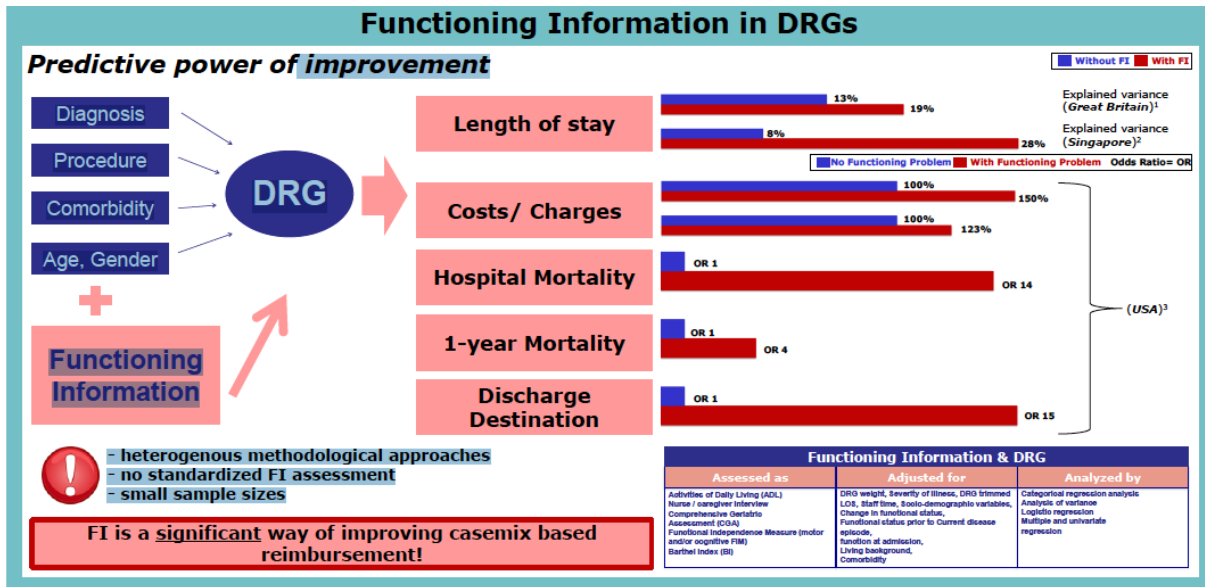
Casemix groupers categorize individuals into statistically and clinically homogeneous groups based on the collection of clinical and administrative data. Adjusting for different levels of acuity forms the basis for healthcare organization comparisons and casemix-adjusted resource utilization. Over the years, these grouping methodologies and their accompanying indicators have been used by healthcare facilities to effectively plan, fund, monitor and manage the services they provide.

ICF provides further explanation in addition to diagnosis and intervention in casemix groups.

ICF can add explanatory power to existing casemix grouping systems. For example, individuals may have a disability, rather than a co-morbidity, which may increase the cost of treatment for a given health condition. In the rehabilitation setting, services sometimes target functioning problems, rather than the medical diagnosis, making the inclusion of relevant categories of functioning especially useful.

Efforts to use the ICF for casemix purposes to date have been summarised (Hopfe et al. 2011). Initiatives are underway in a number of countries to develop improved casemix systems for rehabilitation services (Madden, Marshall and Race 2013).

Figure 1: Functioning Information in DRGs



Hopfe et al.; 2011

3.5. What are the benefits of using the ICF as a common language in clinical settings?

Use of the ICF provides important information beyond the diagnosis of the health condition, alone, about how a diagnosis may impact the life of an individual. This information, shared by professionals and patients, can be used as a basis for communication, program planning, or intervention, as well as reducing overlap between professionals. The shared purpose is usually improvement of the functioning of the individual.

ICF can be used as a framework for sharing information to improve functioning, for instance by identifying environmental barriers which require attention.

ICF, for instance, allows for the coding of facilitators or barriers in the environments in which an individual lives or works and which may affect the success of the proposed intervention. Using information coded in ICF, interventions can be modified to fit specific needs across the various settings for an individual.

How can ICF be used as a tool for communication between professionals? ?

One aim of ICF is to provide a unified, standard language and framework for the description of health and health-related states. It includes interacting environmental factors that contribute to the profile of functioning, disability and health of an individual in different settings. Considering the functioning characteristics and outcomes beyond the body (i.e., Activities and Participation) and the external influences on them (i.e., Environmental Factors), the biopsychosocial model of ICF holistically addresses functioning, disability and health of the individual.

ICF provides a standard language and framework to facilitate communication across services, organizations and agencies.

In clinical settings, ICF can be used to share the functioning status assessment, goals, treatment plans, and interventions, as well as to monitor data with key stakeholders. ICF is a tool that uses everyday terms to facilitate communication across services, organizations and agencies. As a result, it enhances the opportunities for collaboration amongst service providers and may support identification of overlapping services or redundant efforts.

The following questions should be considered when using the ICF as a tool for communication between professionals:

- Who are the professionals and relevant health workers?
- Will other professionals be involved (e.g. in education)?
- What technical language does the profession usually use?
- What information is to be shared?
- What is the level of shared knowledge of ICF?

Within one practice setting, adequately training all professionals in the use of the ICF supports a shared understanding regarding the range of the qualifiers, even if the expertise of each of the professionals covers different content. To ensure successful implementation of ICF in practice, adequate training for all involved professionals in the use, language and terminology meanings is highly important. As a clinical tool, it is important to identify the

content of ICF which is relevant for the professional assessments and of the individual's needs as well as using this content to facilitate collaboration among key players, while matching the interventions with the needs or the purpose of the collaboration. Please refer to section 2.7 to understand how the specifics of professional assessment tools are linked to the ICF.

The ICF is the only universally recognized, comprehensive system for the classification of functioning status associated with health conditions. As such, ICF can be used to provide clinicians and health systems with the information they need regarding functioning status in order to plan and direct treatment appropriately. Furthermore, the wide descriptive capabilities of ICF have the potential to improve treatment by expanding the scope of functional activities that can be documented, thus allowing incorporation of this information in treatment and rehabilitation plans.

How can the ICF be used in goal setting and contribute to intervention planning?

ICF can help identify and describe problems in functioning which can support the identification of treatment "needs" and desired outcomes. Thoughtful implementation of ICF data collection in clinical or other applied settings will maximize the benefit to be obtained from such data. Using ICF has the potential not only to assist the professional in better understanding the needs of the individual, but also to provide information regarding the entire caseload of a professional or the functioning of a clinic or larger system.

Using ICF can identify and describe functioning problems, thus supporting the identification of interventions needed and desired outcomes.

As with the collection of any data intended to inform clinical practice, the timing, sequencing, and frequency of such data collection, as well as the capacity to collect data consistently must be considered. The following are also important to consider:

- The aims of the data collection, the relevant population, and the goals or desired outcomes of the program;
- The set of ICF codes for the data collection; and
- The types of Environmental Factors that may be most important in the specific population or may influence the outcomes considered relevant.

3.6. How can ICF be used to evaluate the outcomes of interventions?

The ability of ICF to describe the functioning profile of an individual, at a given time and at optional levels of granularity, opens the possibility to use the profile as a tool to track changes in the evolution of a health status. Evaluation of such changes may consider change as natural history, as modifications induced by interventions, or as comparison between the expected natural history and the observed evolution.

By tracking functioning status over time using ICF, the outcome of an intervention can be assessed.

Will the ICF enable the formulation of a prognosis over time?

The study of sequential snapshots of the functioning of an individual and the comparison with data on natural history may help in formulating functional prognosis (Mayo et al. 2002). The evolution of the categories being used to describe the functioning of the individual, and the change in the set of categories applied, may be a useful guide to track milestones reached which may also help predict outcome.

Tracking changes in functioning over time using the ICF may be useful to predict outcomes.

Does ICF enable the comparison of different interventions?

ICF provides a systematic description of all aspects of functioning, offering a complete, fully comparable picture of the functioning profile of the individual. Given the systematic approach, functioning profiles with different interventions (e.g. therapeutic procedures or environmental modifications) can be compared to verify the impact of the interventions.

ICF provides a systematic description of all aspects of functioning, allowing for the comparison of the effectiveness of applied interventions.

When the comparison of different interventions is desired, it may be advisable to use an expanded spectrum of activity and participation qualifiers and environmental factors to ensure a fully comprehensive picture of the situation. (See Sections 2.4, 2.5 and ICF).

Box 9: Using the ICF to improve rehabilitation outcomes, Western Cape, South Africa

The ICF conceptualization was used in the development of the Client Enablement & Community Re-Integration Programme. An assessment form was used during multi-disciplinary assessment of patients, for interdisciplinary rehabilitation planning and goal setting. Assessment parameters were defined by the discharge environment and the functional skill requirements for re-integration in society. Discharge planning began early, and included a focus on the ICF areas of life in which the person wished to participate after discharge, and also the ICF environmental factors likely to affect their participation.

This change from a provider-driven system to a patient-driven system approach showed reductions in overall length of stay – having financial benefits to the institution and patient.

Mansur Cloete, WHO-FIC annual meeting 2011. Client Enablement & Community Re-Integration Programme, Western Cape Rehabilitation Center, South Africa, 2005

4 Using the ICF for community support services and income support

4.1 Why use the ICF for support services and income support?

While programmes and services should, in general, be accessible by all, there remains a need for specific measures to provide additional assistance to people experiencing difficulties in everyday functioning. The ICF framework and classification is well suited to the information needs of systems that provide such services and income support. The use of ICF in information systems supporting these services can help improve the quality and cross-sectorial relevance of statistics derived from them.

Services and systems designed to support individuals with functioning problems may be better informed and more consistently and efficiently applied by including ICF measures in their information systems.

Using the ICF for support services and income support has several advantages compared to diagnosis- or impairment-based systems. Support services provide assistance and support to people experiencing difficulties in functioning in everyday life; the support may be provided across all areas of life – in any domain of Activities and Participation. Income support and social security payment systems provide a specific type of support – financial – to compensate for difficulties in areas such as employment or economic life. These systems thus provide compensation for not being able to participate, in contrast to other programs, including support services, which provide additional resources to promote participation.

It is increasingly recognised that the diagnosis of a specific health condition, alone, may not be the most reliable indicator of need for support services or for income support. Functioning concepts are also needed in such service definitions and eligibility criteria and throughout the policy cycle. Community-based comprehensive services are best built around the needs of individuals with disabilities, not the perspectives of the service providers. The ICF framework and classification provides a common language that allows cross-sectorial and multidisciplinary coordination of services to facilitate a person-centred approach.

4.2 How can the ICF assist service planning?

The ICF can support a number of key planning processes as follows:

- Population statistics based on the ICF will identify the need for services and supports. Policies can then be designed specifying which areas of functioning to support. For example, a limited support service program might focus on ICF domains such as mobility and self-care while others might support all areas of activities and participation. *Population statistics based on ICF can be used to identify the need for services and support.*
- Income support systems and community support services require clear and transparent decision-making processes derived from well-articulated policies. The key parameters of these processes may specify key features of the program such as eligibility criteria for access to the program, the quantity of benefits, assistance or funding for a person, or the form of supports available to the individual. Use of the ICF throughout the development of these policies and procedures can assist clarity and coherence.
- Setting thresholds for access to support services and income support schemes often requires a balancing of overall population need against community resources for the program. Population statistics based on ICF enable estimates to be reached of the number of people requiring assistance, and of the numbers to be included in a potential program, using various cut-off points.

Overall, it is vital that information and administrative data, from such schemes, relate not only to the specific parameters of the schemes, but also to the broader population data, via the ICF. This facilitates on-going planning and comparison of demand and supply. It also enables monitoring of scheme outcomes in relation to the goals and planning parameters.

Box 10: National support services data based on the ICF

The ICF is used in the national data collection system of Australia on disability support services, to structure a 'data capture matrix' about the support needs of people. Within this matrix, over 10,000 disability service organisations around the country record information obtained from many different assessment methods. 'Support needs', in nine life areas based on all ICF Activities and Participation domains, form the rows of the matrix and are recorded in one of three categories (set out in the columns):

- needs no help/supervision in this life area:
- sometimes needs help/supervision; or
- always needs help/supervision or unable to do activity.

The value of the 'support needs' questions has been demonstrated. The three categories of need for support are distinct, as are the ICF domains. Analyses showed that, in diverse populations, 'support needs' in one subset of ICF Activities and Participation domains could not be used to predict values in another subset. The utility of having population data, on need or demand for services, and service data, on supply based on the same concepts, has been illustrated by Australian studies of demand for disability support services.

Anderson & Madden 2011

4.3 How can the ICF be used to establish eligibility?

The relationships between biological difference and disadvantage, ability and productivity, or between impairment and needs are very complex. By applying the ICF for eligibility purposes, service systems can not only build more adequate models for establishing eligibility, but also generate data to guide future decision-making in this field. Eligibility procedures in accordance with the Convention on the Rights of Persons with Disabilities and rights-based policy frameworks take into account that disability results from the interaction between individuals with impairments and environmental barriers and that access to services should primarily promote equal opportunities and participation.

Use of ICF concepts can result in clearer and more precise eligibility criteria which can be more consistently and accurately applied.

Simple yes-no models that look at a narrow set of impairment-based criteria for establishing disability are not adequate or evidence-based when the goal of a service is to promote participation. If eligibility procedures are to support a rights-based approach, they have to not only consider “what?” – what needs are to be met and with what assistance - but also “to which end?” – the purpose of the policy. The domains of the ICF can be used to evaluate the interaction between impairments, activity limitations, and environmental factors when defining entitlements and benefits that are responsive to participation restrictions.

The specification of eligibility criteria requires that a ‘threshold’ be set in the spectrum of functioning. Those whose disabilities exceed the specified ‘level’ of the threshold are ‘in’ the service system. Thereafter, these individuals are often referred to as ‘people with disabilities’ for the purposes of the program, even if they may not be referred to as such in other contexts. These criteria must be clearly specified, so as to link logically the assistance provided with the needs of the individual. Expression of these components and links using ICF concepts and terminology promotes consistency and clarity of entitlement and hence of rights.

Eligibility assessment often involves individuals of varying occupations and must be comprehensible to all involved. The ICF provides a common language and framework to integrate information from a range of stakeholders. ICF offers a complete representation of disability and environment and can thus underpin assessment about levels of functioning and difficulties encountered, as well as environmental changes or adaptations that could support the individual, such as assistance in the home or work place, assistance with transport, or environmental modifications.

Box 11: ICF use in threshold setting and eligibility

In Brazil, an ICF based evaluation instrument is being used to operate the BCP (Benefit of Continuous Providing) designated for persons with disabilities in families with very low income. The use of ICF concepts in this instrument resulted in a greater number of parameters being used than previously, helping to more consistently and accurately assess eligibility. Currently, the final decision about benefit concession is made based on a combination of social and medical evaluations. The evaluation instrument in Brazil is titled **Evaluation of deficiency and degree of disability – person with disability**, and includes a section for social and demographic data and a section with 3 ICF components (body functions, activities and participation, and environmental factors). An evaluation is completed by a Social Assistant and another by a Physician.

The section on “Environmental Factors”, including 5 domains and 19 units of classification, is evaluated by a Social Assistant. The “Activity and Participation” component has 9 domains with 30 units of classification and is evaluated by a Social Assistant and Physician, while the “Body Function” component is divided in 13 sub-domains and 22 units of classification and is evaluated only by the Physician.

All items receive one qualifier (no problem, mild, moderate, severe or complete). An algorithm combines the results according to blocks of domains in order to determine eligibility. Professionals involved in institutional studies on the instrument have considered it technically more consistent, and judged that the criteria are clearer, now that the evaluation is based on ICF. It is suggested that this is a new type of technical work that may be also adapted and applied for the assessment of other kinds of benefits.

Brazil. Decree 6214, September 26th 2007: Regulates the Benefit of Continuous Providing (BPC) of social assistance due to the person with disabilities and the elderly according to the Law 8742 of 7/12/1993 and Law 10741 of 1/10/2003, adding a paragraph to art. 162 of Decree 1048 of 6/5/1999, and other matters

http://www.planalto.gov.br/ccivil_03/_ato2007-2010/2007/Decreto/D6214.htm

4.4 Can the ICF support improved service integration and management?

Chapter 5 of the ICF environmental factors component details the services, systems and policies that may enhance or impede participation of an individual. Policy for purposes of income support and for support services vary, but often relate to increasing participation by people with disabilities. This includes participation in paid work and more generally in life and society. Mapping the areas mentioned in the respective policies to the ICF provides insight into how services can be related to the functioning of individuals. This enables other related services to be identified, overlapping responsibilities and services to be recognised, and inefficiencies or inequalities in service delivery to be eliminated.

Linking different systems to ICF concepts will allow for the identification of related services, overlapping responsibilities, or inefficiencies and inequalities in service delivery.

The ICF enables linking or relating of:

- policy and program descriptions and target group specification;
- determination of needs for the program;
- eligibility assessment;
- goal setting and case planning, including assessment of the environment; and
- program monitoring and evaluation.

This information is fundamental to ensuring and managing integrated, person-centred service provision which addresses needs across policy areas and life situations. Using the ICF as a common framework, to understand what services do, will help to avoid duplication or contradictory mechanisms in service delivery. Comparable recording of disability across different policy areas is important for equitable service delivery and accountability. For example, it is possible to see if people with similar levels of difficulty are receiving similar levels of support services irrespective of age such as when there are separate systems for aged or younger individuals with disabilities. Consistency also enables a specific population sample to be compared to the general population, potentially estimating unmet needs.

4.5 Why is the ICF a useful framework to assess service quality?

To fulfil the Convention on the Rights of Persons with Disabilities, countries are expected to take measures across all areas of services to ensure access by all and that the services promote rights and the goals of the Convention. Under the Convention, countries are accountable for adequate quality and levels of service provision. They are expected to monitor their implementation of the Convention and to collect relevant data (Articles 33 and 31). Important conditions of quality are availability and accessibility, choice, the involvement of users in organising and managing services, and the presence of a basic mechanism of quality assurance. The key features and corresponding criteria for quality social services include respect of rights, person-centeredness, comprehensiveness, and self-determination. The ICF allows integration of information from different data sources relevant for the evaluation of effectiveness and efficiency of service provision, continuity, participation and partnership. Using the ICF provides a common language relevant to people in various occupations in the field, and to persons with disabilities and their families so they can contribute equally to the assessment of quality.

ICF allows integration of information from different data sources relevant for the evaluation of effectiveness and efficiency of service provision, continuity, participation and partnership.

With a sufficient combination of information on types of programmes, population and administrative data, as well as information on satisfaction and levels of participation, it becomes possible to evaluate non-discrimination and equality in access to opportunities. This evaluation can be accomplished by comparing key outcomes and access for people in the programmes with the wider population, and the achievement of desired outcomes. The ICF has been found relevant in the monitoring and evaluation of community-based services (Box 12) and community development approaches such as community-based rehabilitation (CBR) (Madden et al 2013).

Box 12: ICF utility for monitoring community-based services

The ICF can be used as an instrument to monitor community-based services and to identify barriers that might prevent people from accessing existing services. The ICF checklist was used in a study in the Eastern and Western Cape of South Africa to interview individuals with disabilities. The specific objectives were to identify the relevant environmental factors, to capture the extent to which they acted as barriers, and to see whether the barriers were different between the two regions.

The sample consisted of 475 respondents, with 377 (79.4%) living in the Eastern Cape, and 98 (20.6%) in the Western Cape. Of these, 66.9 % reported physical problems, 17.9% identified an intellectual impairment, and 12.2% had visual, hearing or speech problems. The distribution of the different types of impairments between the two areas was similar.

The pattern of identified barriers differed between the regions. For example, at the chapter level, people with disabilities in the Eastern Cape reported barriers with “Services” (25%) and “Products and Technology” (23.8%) while in the Western Cape “Natural Environment and human-made Changes to the Environment” (39%) and “Products and Technology” (37%) were reported as the most frequent barriers.

The results of this study indicate that disabled people in the rural areas may perceive fewer barriers within their environment than those residing in urban informal settlements, except with regard to attitudes. Services were widely experienced as greater barriers in the urban Western Cape. The fact that more than 50% of the sample reported access to public buildings as a barrier is of concern, as the study was done seven years after the publication of the Integrated National Disability Strategy (INDS) of South Africa.

Maart et al.; 2007

5 Using the ICF for population-based, census or survey data

5.1. Can the ICF be used to inform population-based data collections?

Information on health and disability can come from a variety of sources requiring different data collection methods. The ICF can inform the data collection process across these various sources and methods, and the manner in which it is used differs accordingly. In clinical settings the relevance of the ICF may be more apparent given the long history of implementing major coding systems (such as ICD). However, the ICF can also be used to inform population-based data collections.

ICF provides a framework for the consistent collection of data to inform population-based statistics which will be internationally comparable.

Until recently, those interested in understanding functioning and disability in a population context were faced with two major challenges: (1) deciding upon an acceptable conceptualization and definition of disability; and (2) choosing an instrument designed to measure disability that effectively operationalized that definition in the population of interest. Historically available instruments produced data lacking in reliability or validity. In the past, many low-income countries reported disability prevalence rates well under 5%, far below the rates observed in some high-income countries, commonly over 10%, some over 20%. What has been lacking is a standardised approach to the measurement of functioning and disability that would allow for the collection of valid data for use within countries as well as for international comparisons of disability statistics.

The ICF provides a framework for the definition and operationalization of disability in surveys and censuses. The World Report on Disability (WHO & WB 2011) makes specific recommendations to enhance the availability and quality of data on disability. These include the adoption of the ICF as a framework for the development of questions on disability, improved comparability of data, the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability, and the collection of national population census data according to the recommendations from the UN Statistical Commission (Statistical Commission, 1994).

Box 13: Defining severity and thresholds in population data - a survey 'link' to ICF qualifiers

Estimated prevalence rates vary widely across and within countries. The WHO World Health Survey, a face-to-face household survey from 2002–2004, is the largest multinational health and disability survey ever done. It used a single set of questions and consistent methods to collect comparable health data across countries.

The conceptual framework and functioning domains for the World Health Survey came from the ICF. The questionnaire covered the health of individuals in various domains, health system responsiveness, household expenditures, and living conditions. A total of 70 countries were surveyed, of which 59 were countries representing 64% of the world population, producing weighted data sets that were used to estimate the prevalence of disability of the global adult population aged 18 years and older. Possible self-reported responses to the questions on difficulties in functioning included: no difficulty, mild difficulty, moderate difficulty, severe difficulty, and extreme difficulty. These were scored, and a composite disability score calculated, ranging from 0 to 100, where 0 represented 'no disability' and 100 was 'complete disability'. This process produced a continuous score range. To divide the population into 'disabled' and 'not disabled' groups, it was necessary to create a threshold value (cut-off point). A threshold of 40 on the scale 0–100 was set to include those experiencing significant difficulties in their everyday lives within estimates of disability.

World Report on Disability. Chapter 2. Geneva: World Health Organization & World Bank. 2011.

A 'Training manual on disability statistics' (WHO & UNESCAP 2008) provides valuable guidance on how to operationalize the concepts of functioning and disability as represented in the ICF within data collection, dissemination and analysis.

5.2. What is the difference between collecting survey data and clinical data?

Data collected in a clinical setting may differ from data collected in population-based surveys in several ways including source, purpose, and the method(s) for collection. These differences affect how the ICF informs data collection.

Clinical data are often collected by professionals for the purposes of evaluating the level of functioning of individual, specific aspects of functioning, and the need for or impact of services. For these purposes, the classification and coding system components of the ICF have direct application.

Clinical data tend to focus on an individual, while population-based survey data identify population characteristics or changes in these characteristics over time.

Surveys may be used to collect data in a variety of contexts. Population-based surveys, such as Censuses or surveys run by the Ministry of Health, National Statistical Offices and other data producers at national and international level, collect data from the whole population or a predetermined sample of the population. While data are collected from or about individuals, the intent of the data collection is to identify population characteristics and changes in these characteristics over time or across subgroups of the population. Such surveys may focus specifically on disability, or disability may just be included as one component of a larger, general purpose survey. Researchers may also use surveys to collect information for specific projects. Research-based data collections may be more limited in geographical scope than are national or regional population surveys.

The type and scope of information collected will depend on the objectives of the study. Information collected may include various aspects of the need for services and service provision, monitoring the level of functioning, specific aspects of functioning in the population, or an assessment of inequalities of access or opportunities within a population. Survey and census data collections are both often designed to serve multiple purposes, and to be aggregated to various geographic levels (local, regional, national). Data are often not collected by clinical professionals, but by trained enumerators or interviewers using a structured questionnaire, or by researchers who might use less structured data collection tools.

The ICF can be used as a universal framework for disability data collection related to policy goals of participation or inclusion. Its use can improve how data are collected and increase the probability that different sources of data relate well to each other. The ICF should be used as a reference text or framework, however, rather than as a direct source of questions. Given the inherent limitations of the survey format, it is not feasible to craft a questionnaire that would cover the scope and level of specificity included in the ICF in its entirety. The objective of a population-based survey should be to develop a *coherent, relevant, valid and feasible* set of questions that meets the purposes of that survey.

Box 14: Defining severity and choosing a cut-off

The 2000 Brazilian Census made use of the following response options for questions on disability: no difficulty, some difficulty, severe difficulty and unable. When final results were published, Visual Disability represented almost 50% of all disabilities, and this was considered a distortion. However, further evaluation of the responses showed that 14.060.946 respondents indicated a mild problem (“some difficulty”), 2.435.873 severe (“severe difficulty”) and 148.023 complete (“unable”). The available response options permitted the identification of different target-populations, which would not have been possible with “yes-no” type answers.

Instituto Brasileiro de Geografia e Estatística (IBGE). Censo 2000. Available at:

<http://www.ibge.gov.br/home/presidencia/noticias/20122002censo.shtm>

5.3. What is the starting point for using the ICF in censuses and surveys?

Population-based survey research is predicated on the formulation of a research question that defines the specific purpose for the collection of data. In terms of data collection, the ICF model covers all dimensions of disability including body functions and structures, activities and participation, together with associated impairments, limitations, and restrictions. ICF also includes environmental and other factors that may affect the above components. The challenge is to relate the purpose of the data collection to the ICF model, design and test questions that meet this purpose, analyse

the data and finally, through interpretation of the results, to relate the findings back to the ICF framework.

ICF is comprehensive, with components covering all dimensions of disability, including associated environmental factors, that can be operationalized when designing questions for censuses or surveys.

5.4. How can survey purposes be related to the ICF?

Relating or positioning the specific objectives for data collection within the ICF framework will aid in the identification of domains and the formulation of questions.

Three broad categories of purpose have been recognized in collecting survey data on functioning and disability (see for example WHO 2011; Madans et al. 2004):

- to monitor the level of functioning in the population
- to provide information on the need for and use of services, and
- to assess the equalization of opportunities.

Monitoring levels of functioning includes estimating prevalence of disability and analysing trends in various aspects of functioning. The level of functioning in the population is frequently considered a primary health and social indicator. Service-related information at the population level includes, but is not limited to, the need and receipt of housing, transportation, assistive technology, vocational or educational rehabilitation services, and long-term care. Also included are issues of awareness of services available and whether these are, in fact, accessed. The assessment of equalization of opportunity may include monitoring and evaluating outcomes of anti-discrimination laws and policies, as well as service and rehabilitation programs designed to improve and equalize participation of all individuals in all aspects of life. The intent of these assessments is consistent with that of the United Nations World Program of Action concerning Disabled Persons and the United Nations Convention on the Rights of Persons with Disabilities. While it is helpful to use these three broad categories as a general guide to clarify the purpose of specific data collection, it is necessary to clearly describe the objectives of the data collection prior to developing specific questions. Once specific objectives are described, the ICF can be used to guide question development.

Relating specific survey objectives to the ICF framework can help identify domains to target for the development of survey questions.

5.5. Can standard question sets be used?

Developing new question sets is a complex and expensive activity. This applies to question sets consistent with ICF as it does for any other new question set. While it may be necessary to develop new questions to meet specific needs for some projects, it may be possible to use standard question sets for others.

An advantage of using a standard set of questions is that the comparability of data across collections is increased. Significant resources are often devoted to the development of these standard sets, and many have been collaboratively developed for use cross-culturally. There is generally a significant amount of information available on these question sets describing the conceptual model upon which they are based, as well as what is known about their quality characteristics and how they perform in various settings. It is still critical that the correct set of questions be chosen for the stated objective and for the population being studied, as well as the context of the collection. The question set chosen should also be consistent with the ICF framework. Users should evaluate all available information about the sets and determine whether they fit the objectives of the study and have been sufficiently evaluated. This is only possible if the developers of the question sets make information about the questions available and readily accessible. Improved methods of question evaluation are being developed, and there is growing expectation that information on the characteristics of developed question sets will be provided.

Also of importance in determining if a standard question set will meet the objectives is the nature of the data collection mechanism. Information on disability and functioning can be collected in a variety of survey formats, from national censuses to in-depth disability surveys. Disability questions are often included in population censuses. The characteristics of the data collection methods will affect whether or not a particular question set will provide the necessary information. The manner in which censuses are collected may affect their effectiveness in obtaining information on disability and functioning; for instance, if the census is restricted to a small number of questions or if data are collected by a large number of interviewers with limited training whose primary objective is to enumerate the entire population. It may also be difficult to obtain information on mental health related functioning limitations on a census. However, for some countries, including questions on disability in a census is the best way to ensure that disability will become part of the ongoing data collection process. Furthermore, such censuses often also collect information on other key aspects of life, thus providing an attractive mechanism for obtaining information on social inclusion.

Small question sets may be added to other multipurpose surveys, or surveys whose primary objective is to obtain data on other subjects such as living standards, employment, education or housing. The use of the same small set in all surveys conducted in a country allows for information on the characteristics of the population with disabilities to be analysed across data collection systems, providing a greater wealth of information on social inclusion.

Longer sets of disability questions may be incorporated into health and health care surveys, or disability might be the sole focus of a survey. Surveys that focus on disability have the advantage of being able to produce information in greater detail covering more aspects of the ICF model. This allows the analyst to investigate the complex relationships among ICF components and to investigate potential causal mechanisms so as to inform the development of interventions to enhance functioning.

It may be possible to use existing standard, ICF-based question sets for some projects, however, it will sometimes be necessary to design new sets to address the specific requirements of other projects.

Box 15: National Disability Survey (NDS) in Ireland

The 2006 National Disability Survey (NDS) was conducted by the Central Statistics Office (CSO) after the 2006 census. A nationally representative sample of more than 17,000 people (adults and children) was chosen, based on responses to the 2006 Census of Population. The sample comprised 15,000 people with disabilities of all types in private households, 2,000 people without disabilities in private households, and 700 people with disabilities of all types in hospitals, nursing homes and homes for children. The survey was conducted by personal interview. The first report on the findings of the survey was published in 2008 with a second report in 2010 (www.cso.ie).

The NDS was preceded by a pilot exercise conducted during 2002–2004 by contractors to the National Disability Authority (NDA) (see www.nda.ie for the report on the Pilot). The pilot explored and then recommended the WHO ICF as the framework for the survey; developed interviewer guidelines for use by the survey staff; and addressed concerns, including ethical issues, raised by an extensive consultation process. The report by the pilot team (Browne et al., 2004) provided the basis for the recommendations from the NDA to the government. The decision was made to use the ICF framework, as had been recommended by the pilot. Further details of the pilot exercise, the guidelines developed, the NDS methodology, the four questionnaires (adults or children in private households, adults or children in non-private residential settings), and the NDS findings are available from the CSO and NDA websites. The benefits of the ICF framework are shown, particularly in the findings on prevalence and on environmental factors.

Browne et al. 2004, Brady and Good 2005, CSO 2006 and 2010

5.6. What is involved in the design and testing of relevant survey questions?

In developing new survey questions to measure functioning and disability, a notable challenge is to account for the numerous ways that respondents across differing cultures, languages and socio-economic conditions might interpret and cognitively process those questions. The challenge is further heightened because disability concepts are complex, involving numerous and varied meanings, attitudes and types of experiences across individuals and socio-cultural sub-populations. The ICF framework should be used to identify what aspects of functioning and disability the questions should address.

Survey questions developed using the ICF framework, should be subject to extensive cognitive and field-testing to ensure validity across populations.

The development of questions for use in censuses and surveys requires a process of testing and revision to ensure appropriate construction and validity; that the questions are in fact measuring what they were intended to measure. Further, cognitive testing provides evidence of the comprehension of the respondents (how they understand and interpret the question), their retrieval process (ability to search their memory for relevant information); their judgment (their evaluation of the retrieved information in terms of the question asked); and their response (whether they are able to provide the information retrieved in the requested format). Cognitive testing identifies both the intended and unintended interpretations of questions as well as errors in question construction and provides indications of where question revision may improve the responses. All these steps help to differentiate the reasons for differences in survey estimates, and to interpret response bias relating to social and cultural circumstances.

Field-testing of the questionnaire can provide additional evidence on the extent to which these particular patterns of interpretations are prevalent in a larger, random sample of respondents. Furthermore, the results of the cognitive testing can be used to inform the field test instrument.

Question evaluation through cognitive and field testing allows poorly performing questions to be revised prior to implementation in large, expensive surveys, ensuring that the questions capture the intended concept. This should support international comparability of the data, as well as comparability across different sectors of the population in one country.

When designing and testing survey questions it is important to consider who will be answering the questions. As a general rule, it is preferable to ask questions directly to the subject, but this is not always possible. In some cases, such as censuses, the data collection is designed so that one household respondent answers for all members of the household. In other cases, the subjects cannot respond for themselves due to ill health or a functioning limitation. It is important to obtain information on all individuals in the target population, so proxy respondents should be used in cases where the subject cannot respond. The proxy should be someone knowledgeable about the subject, and the fact that a proxy respondent was used, as well as the reason(s) for the proxy, should be documented. As it is likely that proxies will be used in at least some cases, questions should be tested with proxy respondents, as well, to ensure appropriate validity.

5.7. Should analysis of data and interpretation of results also refer to the ICF?

It is of value for census or survey data to be analysed within the larger context of the ICF. For example, a particular data collection might be focused on body functions in the area of sight. When discussing these findings, however, it may be useful to place the findings within the ICF framework. This may help to inform issues of potentially related limitations in activities or participation such as in using transportation or engaging in employment. The intent is not to draw conclusions about possible relationships, but to clarify where the specific findings might fit in the overall framework. That is, what aspects of disability do the findings address and which aspects are not addressed?

Referring specific survey findings back to the ICF framework will help to contextualize these within the broader experience of disability.

5.8. What relevant question sets currently exist?

Many question sets have been developed for use in population surveys, and work is actively underway to develop new question sets. The module on “Health State Descriptions” of the WHO World Health Survey consists of a set of questions, based on ICF, covering Overall Health, Mobility, Self-Care, Pain and Discomfort, Cognition, Interpersonal Activities, Vision, Sleep and Energy, and Affect. The full questionnaire of the World Health Survey can be accessed at <http://www.who.int/healthinfo/survey/instruments/en/index.html>.

There are a number of existing question sets, such as the WHODAS 2.0, which have been developed and used internationally, which can be considered for use if relevant to purpose.

The WHO Disability Assessment Schedule 2.0 (WHODAS 2.0) includes activity and participation domains and has undergone validation studies in a number of countries. The WHODAS 2.0 is an example of an existing question set which provides a standardised method for measuring health and disability across cultures. For more information on the WHODAS 2.0, see Box 16 and <http://www.who.int/classifications/icf/whodasii/en/index.html>.

The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) developed a questionnaire based on WHODAS 2.0 and ICF and used it in a survey of five countries in the Asia/Pacific Region. For more information on this activity, see: <http://www.unescap.org/stat/meet/widism4/index.asp>.

Box 16: WHODAS 2.0 use

The World Health Organization Disability Assessment Schedule is a generic assessment instrument developed by WHO to provide a standardized method for measuring health and disability across cultures. It was developed from a comprehensive set of International Classification of Functioning, Disability and Health (ICF) items that were designed to measure the difference made by a given intervention. This is achieved by assessing the same individual before and after the intervention. A series of systematic field studies was used to determine the Schedule’s cross-cultural applicability, reliability and validity, as well as its utility in health services research. WHODAS 2.0 was found to be useful for assessing health and disability levels in the general population through surveys, and for measuring the clinical effectiveness and productivity gains from interventions.

WHODAS 2.0 captures the level of functioning in six domains of life:

Domain 1: Cognition – understanding and communicating

Domain 2: Mobility – moving and getting around

Domain 3: Self-care – attending to one’s hygiene, dressing, eating and staying alone

Domain 4: Getting along – interacting with other people

Domain 5: Life activities – domestic responsibilities, leisure, work and school

Domain 6: Participation – joining in community activities, participating in society.

Given the importance of summary measures, one important application of WHODAS 2.0 has been to provide information on the extent of disability in different populations, including in lower resource settings (Maart and Jelsma 2012).

The Washington Group on Disability Statistics, a United Nations Statistical Commission city group, has also developed a question set for use in censuses and surveys. It applies an ICF-based approach to the definition and measurement of disability and follows the principles and practices of national statistical agencies. This question set may be added to any survey. The short set of questions covers six functional domains (activities), namely vision, hearing, mobility, cognition, self-care, and communication. The questions asking about difficulties in performing certain activities because of a health problem are as follows.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty with self-care, such as washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating (for example, understanding or being understood by others)?

Each question has four types of response, designed to capture the full spectrum of functioning from mild to severe: no difficulty, some difficulty, a lot of difficulty and unable to do it at all.

The six questions listed above cover some important areas of activities and participation, but not all, while the response categories capture a range of severity of the difficulty experienced. Multiple disability scenarios may be described depending on the domain(s) of interest and the choice of severity cut-off. There is more than one way to capture disability through the application of this set of core questions, resulting in several possible population prevalence estimates that will vary in both size and composition.

For the purpose of international comparability, the Washington Group recommends that the following cut-off be used to define the populations with and without disabilities for the purpose of computing and reporting disability prevalence rates when using their short list of questions.

“The sub-population disabled includes everyone with at least one domain coded as a lot of difficulty or cannot do it at all.”

Other cut-offs may be used for other purposes but it is always important for the data user to define how disability status is derived. This approach was taken in a 2006 survey of living conditions in Zambia (Loeb et al 2008). Here it was found that: 14.5% of the population reported ‘some difficulty’ in at least one domain; 8.5% reported ‘a lot of difficulty’ in at least one domain; and 2.4% reported that they ‘cannot do it at all’ in at least one domain.

The Washington Group has recently finalized an extended set of questions on functioning (ES-F) for use in surveys that expands upon the six short set domains (vision, hearing, cognition, mobility, self-care, and communication) to include additional functioning domains (upper body functioning, affect, pain, and fatigue) and more information per domain, such as the use of assistive devices/aids and functioning with and without assistance. This set of questions is designed for use as a component of population surveys, as a supplement to surveys, or as the core of a disability survey.

Work is currently underway on other extended sets including a set specifically targeted to children and one focusing on the environment. Details of the organization of the Washington Group and their accomplishments are available online at: http://www.cdc.gov/nchs/washington_group.htm

Questions on functioning may be added to censuses or surveys, including surveys whose main focus may be outside the area of health and disability. If such questions are added on an on-going basis, it is possible to monitor trends across time and to evaluate the effect of policies that are aimed at addressing the factors affecting activity limitation and participation restriction.

5.9 How can population data help examine equal opportunity outcomes?

Population based survey data can be used to investigate and monitor equal opportunity outcomes and social inclusion to address the requirements of the Convention on the Rights of Persons with Disabilities. However, in order to determine if individuals with disabilities have achieved full social inclusion, it is first necessary to identify who they are.

The assessment of equalization of opportunity as a purpose for measuring disability can be achieved in a census. Over the course of time, a census may allow for such assessment by monitoring and evaluating outcomes for individuals with disabilities, thus enabling inferences to be drawn about the success of social measures such as anti-discrimination laws and policies, or service and rehabilitation programmes designed to improve and equalize the participation of individuals with disabilities in all aspects of life.

For the purpose of determining disability status using census data, individuals with disabilities may be defined as those who are at greater risk than the general population of experiencing limitations in performing specific tasks (activities) or restrictions of participation in society. In the example of the Washington Group questions described in section 5.8, this group could include persons who experience difficulties in one or more of the six core domains, such as walking or hearing, even if the difficulties they experienced were alleviated by environmental factors, such as the use of assistive devices, living in a supportive environment, or having plentiful resources. Some of these individuals may not experience restrictions in participation when the necessary adaptations are made at the level of the person or in their environment. They would still, however, be considered to be at greater risk than the general population for participation restrictions due to the presence of difficulties in the six core domains. As such, in the absence of accommodations, levels of participation in this population might be jeopardized.

As censuses frequently also contain a wide range of questions about aspects of life such as housing, employment, transport, income and family, outcomes for people with disabilities (as defined in this collection) can be compared to those of the general population when relevant questions are included. This can provide opportunities to examine equal opportunity outcomes.

Population based survey data can be used to investigate equal opportunity outcomes and social inclusion in terms of the requirements of the Convention on the Rights of Persons with Disabilities.

6 Using ICF in education systems

6.1. Is the ICF useful in educational settings?

The ICF is useful in education settings as it helps to overcome past approaches of describing or labelling disability that may have led to segregation or discrimination in education. The underlying bio-psycho-social model of ICF does not deny the impact of impairments on functioning; rather it identifies functioning known to be important for participation at a given age. Through its component of activities and participation, ICF is able to enhance the description of health conditions and impairments with information focusing on learning and development.

ICF is able to enhance the description of health conditions and impairments with information focusing on learning and development.

ICF can be used in all education settings to support continuity during entry into education, and during the transitions from one educational level to the next or into subsequent work and employment. Using ICF in classroom settings as well as school-related clinical settings provides a common language for the coordination of services provided by educational, social and health systems.

6.2 Can ICF help to bridge diagnostic and educational information?

In order to be relevant for education, information on problems, deficits or impairments should be understood in the context of participation in education. It is important to note that relationships between impairment and academic achievement or between capacity and performance, in a given educational environment are never straight forward, but need to be explored and understood. In the context of education, functional information on impairments should be combined with information about functioning relevant for learning and understood in the context of the specific requirements for successful participation that may differ considerably from one educational setting to another.

ICF provides a framework to bridge disability-based and curriculum-based information as well as clinical and educational information.

ICF provides a framework to bridge disability-based and curriculum-based information as well as clinical and educational information. Functional assessment tools such as the Wee-FIM (Functional Independence Measure for Children) or the PEDI (Paediatric Evaluation of Disability Inventory) provide information on functional limitations, and ICF can help link this information to domains that are important for education including 'Learning and applying knowledge'.

6.3 Can the ICF be used for assessment in education?

The concept of participation, as defined in the ICF as “*involvement in life situations*”, is a helpful starting point to explore potential causes and dynamics between environment and learning. The ICF can serve as a bridge between assessments focussing on health, development, curriculum and social dynamics. It provides a neutral framework that can be linked with norm-referenced or criterion-referenced measurements. In the context of a health condition, the full ICF can be used to understand the impact of impairments, activity limitations and environmental factors on participation in education as a major life area.

The ICF provides a neutral framework that can serve as a bridge between assessments focusing on health, development, curriculum and social dynamics.

ICF is a framework to describe a situation with regard to human functioning. ICF conceptualises education in the context of health, not in the context of competence, but can help bridge assessment results from both perspectives to provide a comprehensive picture of the functioning of a child in a specific educational environment. This can support national curricula or standards, which are otherwise generally linked to assessment or testing procedures that focus on subject-related knowledge.

A major reason for assessment in education systems is to gain information on achievement or progress in learning. Problems in learning or developing, adjusted for age, may motivate assessment for the identification of a disability. It is not always clear to which extent difficulties in learning might be due to a health condition, to social disadvantage, or to inadequate teaching.

6.4 Can ICF be used to understand participation in education?

Participation in ICF is defined as ‘involvement in life situations’. In the context of education, this means being actively engaged in tasks, activities and routines that are typical for children of that age in a given education system. Education is a major life area in ICF, and all students should have the rights to participate in education and to be given the opportunity to develop their talents and potential, whether they have disabilities or not. ICF can be used as a framework to develop indicators to measure the over-all participation of children in education, and can help identify children with disabilities.

ICF can be used as a framework to develop indicators to measure the over-all participation of children in education.

Participation in the context of education is also about creating a voice for parents and children with respect to their education. Article 12 of the Convention on the Rights of the Child states that ‘the views of the child [should be] given due weight in accordance with the age and maturity of the child’.

Education as a life area is made up of many life situations, including sitting in a classroom, interacting with teachers and peers, playing in the school yard, or going on a school trip. These life situations involve carrying out routines, specific sequences of tasks, or activities that are typical for the situation. There are several ICF-compatible assessment instruments measuring participation, such as the CASP (Child and Adolescent Scale of Participation) or the PEM-CY (Participation and Environment Measure for Children’ and Youth). To fully understand participation in education, attention should be given to how tasks or routines might be altered to ensure over-all participation in a given environment. It is not enough to simply measure the performance of the student in carrying out pre-defined tasks in a pre-defined environment.

6.5 Can ICF be used to analyse educational environments?

Education in ICF is also conceptualised as an environment where different settings or life situations are created. ICF as a classification and framework can help understand the interaction between educational environments and the participation of students with disabilities. Participation can also be viewed as an indicator for the inclusiveness of education services, systems and policies.

ICF can support assessment of the interaction between the functioning of the student and their environment.

Education systems, services and policies are included in Chapter 5 of the environmental factors. Article 24 of the Convention on the Rights of Persons with Disabilities refers to the right to education and the requirement of states to ensure an inclusive education system.

ICF is a framework which represents information on the quality of educational environments as it may relate to functional difficulties of students. Content from the ICF environmental factors chapters can be arranged to represent educational settings. ICF can be used to bring together information on the quality of educational opportunities, the availability of support systems, or the beliefs and attitudes of teachers or other professionals working in education systems. Existing tools and standards to assess all aspects of school environments including “opportunities to learn” can be mapped to ICF and matched with the functional profiles of students. Therefore, ICF can support assessment of the interaction between the functional characteristics of the student and their environment.

6.6 Can ICF be used to establish eligibility in education settings?

Being eligible implies gaining access to services, benefits, accommodations or compensations that are generally not provided to all individuals. Rather than determining eligibility based on the diagnosis of a health condition or severity of impairment, alone, ICF can be used to identify the participation gap and to set functioning goals. The means to reach these goals can then be determined.

The ICF can be used to identify the participation gap and to set functioning goals.

The Convention on the Rights of Persons with Disabilities requires inclusive education systems providing adequate support to ensure access and participation for all students, including those with disabilities, to be provided by the state. For some, this may require additional support, assistance or adaptations to facilitate or promote learning and development. ICF provides a framework and common language to link disability in and to the current educational environment.

Setting thresholds is necessary to ensure equitable and effective use of available resources. ICF facilitates the combination of different thresholds in order to focus, not only on the severity of impairment, but also on minimal thresholds for participation. A functional approach to establishing eligibility allows for different thresholds and cut-off points to be used for different purposes. Examples might include criteria for passing exams, being admitted to schools or receiving additional support. This will make far-reaching decisions, such as a transfer to a special school or a temporary exclusion from the regular classroom due to mental health problems, more transparent.

Box 17: ICF-based Standardised Eligibility Procedure

Since January 2011, the Swiss cantonal education systems have started to implement a multidimensional, context-sensitive procedure to establish eligibility within education systems. The procedure is based on the International Classification of Functioning, Disability and Health (ICF) in accordance with the principles of the UN Convention on the Rights of Persons with Disability. The procedure consists of two parts, (1) organising information on the present situation of the child, and (2) organising information on the future situation of the child as envisaged by the individuals involved. Using ICF as a model and classification, the different factors influencing eligibility-related decisions (e.g. impairments, activity/participation, environment, and personal factors) can provide the basis for a transparent decision-making process to which parents and the child actively contribute.

Procedure available at: <http://www.edk.ch/dyn/23728.php> (German, French, Italian)

See Hollenweger; 2011

6.7. Can the ICF be used for goal-setting?

ICF can provide a basis for goal-setting through supporting integration of assessment information from diverse sources, settings and perspectives. In order to promote active learning and development of students with disability, the views of all stakeholders should be considered. For example, self-assessment by a student may differ considerably from the assessment performed by a teacher, therapist or school psychologist, but each is important to consider. In settings where teachers and students are involved in direct interactions, assessment should be an on-going process. This process brings together diverse observations, test results, reports and other assessment information to inform goal-setting (formative assessment or assessment for learning).

ICF can provide a basis for goal-setting through supporting integration of assessment information from diverse sources, settings and perspectives.

Goal setting is something done by all professionals working with children, whether explicitly or not. In some cases, goal-setting can lead to contradictions and dilemmas, whether the goals are developmental, impairment-specific, or even general educational. The ICF framework helps the user differentiate between and balance different goal dimensions, such as goals directed to alter an impairment (e.g. improve voice functions), compensatory goals (e.g. work on communication skills to limit impact of a speech impediment), developmental goals (e.g. be able to communicate adequately in different social settings) or curricular goals (e.g. literacy skills as defined by the Programme of International Student Assessment, PISA).

ICF helps the user judge fit between environmental factors and the functioning of the individual to decide whether goals should be stated to target functional problems, to adapt the environment, or both. Different professionals, the parents and the child may hold different opinions as to the best way forward. ICF is a useful framework to clarify and integrate goals set by different professionals and other persons involved. The integration of the views of the child and the parents is especially important in individual educational planning because the child must be able to actively participate in reaching the goals.

6.8. How can ICF be used to evaluate student outcomes?

ICF can be used to structure evaluation of the effectiveness or efficiency of interventions carried out in the context of education, as is done in clinical or other intervention settings. In educational settings, goals are generally broader than in clinical settings and interventions tend to be less specific and of longer duration, targeting learning and development rather than specific functions. ICF provides a framework to map goals before, during and after the intervention. Diverse qualitative and quantitative information from different sources can be integrated using ICF to provide a broader picture of the student outcomes.

ICF can be used to structure the evaluation of efficiency and effectiveness of interventions framed within the educational setting, as is done in clinical or other intervention settings.

Participation is a central construct in ICF and is the “boundary concept” between health and education. It may be understood both as process (involvement in a life situation) and an outcome (performance) of education. ICF is well positioned to serve as a tool for monitoring the implementation of the Convention on the Rights of Persons with Disabilities, article 24 on education, and to measure the extent to which a given education system is able to create learning opportunities for students.

If ICF is adequately linked to existing quality indicator systems, it may be used as a tool for evaluating student outcomes which accommodate potential impacts of impairments and activity limitations on learning and achievement. Due to its universal approach to human functioning, ICF allows for an integration of disability-related information with educational accountability procedures. Unlike traditional disability categories, ICF allows the user to link functioning with achievement and non-academic outcomes. Differences in student outcomes can be compared with the diversity of student population which will help measure school success by the educational success of all learners.

6.9 Can ICF facilitate cooperation and integrate different perspectives?

Different stakeholders have different perspectives and potentially different priorities when it comes to the education of students with disability. ICF can support the development of tools and procedures that facilitate communication and coordination across sectors and settings.

The bio-psycho-social model of ICF provides entry points for the diverse views, interests and expertise of professionals, policy makers, parents and the public. With ICF, a common language and standardised decision-making procedures can be developed and implemented to ensure that all parties are involved in problem-solving.

ICF is a complex information system and requires proper introduction and training for correct use. This is certainly the case if an ICF-compatible structure is used by students for self-assessment, for evaluation of environmental barriers, or in conversations with teachers and parents about the learning, development and functioning of the student. Content and format should be meaningful and accessible to students, and should contribute towards supporting them as active learners. For example, pictograms and drawings can be used to represent content from ICF. Student portfolios could be organised along the life domains in ICF to illustrate student progress. If self-reports of the progress, interests or difficulties of the student follow the same structure as the assessment tools used by teachers and therapists, then students also become partners in the assessment, planning and evaluation processes.

ICF can support the development of tools and procedures that facilitate communication and coordination across sectors and settings.

7 Using the ICF for policy and program purposes

7.1 Why is it important to use standard disability concepts across different policy areas?

Disability is a cross-cutting issue affecting all policy domains. Historically, it was common for different policy areas each to have developed their own, unique working definitions and concepts surrounding disability. With increasing economic and demographic pressure on social welfare systems, countries are under pressure to develop cross-sectorial roadmaps to ensure sustainability. A common approach to understanding disability using the ICF can serve as a foundation for the shift from allocating welfare benefits to using social policy as a tool to build a more inclusive society (e.g. from compensatory policies to integrative or enabling policies).

It is important to use standardized concepts when developing policies related to cross-cutting issues, such as disability.

Comparable recording of disability across different policy areas and the development of compatible statistics and indicator systems are important for equitable systems of service delivery and monitoring. For example, it is possible to see if individuals with similar levels of difficulty are receiving similar levels of support across the age spectrum in situations where there are different systems for aged care and younger people with disability. Consistency also enables a client population to be compared to the general population and unmet needs to be estimated.

Cross-sectorial policies focusing on social development as promoted, for example, by the World Bank (2007) should re-think 'disability', and conceptualise it as something that can be changed as well as managed. The ICF provides a framework to operationalize disability accordingly and help harmonise compensatory, integrative and enabling policies. Working with multiple thresholds and environmentally sensitive concepts such as 'participation gap' is required to inform social policies and promote mainstreaming of disability. It may be an advantage if multiple thresholds are used, thereby enabling different analyses and varying comparisons. ICF-based eligibility definitions, for example, create thresholds aligned with policy purposes.

7.2 Why use the ICF in policy-making?

'Disability' can be understood as many different things and policy-makers must confront complex and often ill-defined problems. There may be different opinions regarding cause and effect, types of interventions, or adequacy of proposed solutions. There may be substantial uncertainties as to the financial consequences of changes in policies or conflicting views and opinions from different stakeholders.

Using the ICF as a framework and common language can facilitate policy development.

Using the ICF as a framework and common language may facilitate policy development. For example, Germany introduced the ICF as the basic framework in its Ninth Social Security Code (Neuntes Sozialgesetzbuch), while Japan uses the ICF not only in its national legislation and policies, but also in fields related to disability, such as long-term care (Box18). The ICF may also build links between the Convention on the Rights of Persons with Disabilities, available data on the current situation, opinions held by different constituencies, and envisaged changes in policies or programs. Countries that have signed and ratified the Convention on the Rights of Persons with Disabilities are faced with the need for policy development in order to fulfil their obligations.

Box 18: ICF in Asia and the Pacific

ICF has been introduced to many health-and-disability-related areas of policy and legislation in Asia and the Pacific Region, for example:

Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-based Society for Persons with Disabilities in Asia and the Pacific, the declaration by the representatives from Asian and Pacific countries in October 2002, stated that 'a wider use of ICF in countries of the region will be expected to provide a base for a common system of defining and classifying disability.'

'Basic Programme for Persons with Disabilities': The ten-year plan for services for people with disabilities by Japan's Cabinet Office (2002), stipulates that 'ICF should be used for better understanding of diversity of disabilities.'

Health and personal care policies: ICF was introduced to many areas, including rehabilitation, long-term care and its management, disability prevention, support for independent living of persons with psychiatric disabilities, national examinations for health and health-related professions, and others.

Other areas: ICF was also introduced to special education, overseas developmental aids, and prevention of new functioning problems after natural disasters, among other things.

Okawa & Ueda 2008

The best way to deal with complex social issues, such as the impact of disability in different life areas, is to ensure the following: an adequate understanding of the problem, consultation or participation of all constituencies, evidence-based decision-making, and analytical rigour throughout the policy cycle. This may be seen as problem identification, agenda setting, policy development, policy implementation, and policy evaluation. Visions and broad social goals should guide the formulation of policy targets, given available resources and other constraints. Using the ICF as a common language throughout the policy cycle can facilitate the coordination and harmonisation of different governmental initiatives, policy components, and the related activities of different groups. In the process of policy development, the ICF can be used as an underlying map to create knowledge-sharing tools, data and information tools, and process guidance tools which easily speak to each other.

7.3 How can the ICF help raise awareness and identify problems?

The Convention on the Rights of Persons with Disabilities and Chapter 5 of the ICF environmental factors component outline the services, systems and policies that may enhance or impede participation by an individual. Mapping parameters of national policies to ICF provides insight into how current service provision in different policy areas relates to functioning.

Mapping parameters of national policies to ICF provides insight into how current service provision in different policy areas relates to functioning, and what gaps may exist.

When developing policies, good first steps include identifying the problems and gaining an understanding of how these problems affect the wider public. From a social development perspective, understanding problems related to participation restrictions experienced by individuals with disability is paramount.

Perhaps the most obvious way in which the ICF can support identification of problems in policies and society is via ICF-based statistics and indicators:

- When a range of population-based statistics are based on a common framework and use an ICF-based 'disability identifier', then the different experiences of individuals with disability compared to others in society can be described. One such example is the significantly lower employment rates among those with disability compared to non-disabled individuals present in many countries (OECD 2003). Via such comparisons, it might also be found that individuals with disability are less likely than others to be involved in a sport, for example, despite interest or desire to participate. Further inquiry may reveal whether this is because of lack of suitable sports, inaccessibility of venues, attitudes of sports administrators or some other cause. If the causes are found, policies and programs can be changed accordingly.
- When administrative and systems-based data are based on ICF and share common concepts with population data, 'demand' (from the population data) and 'supply' (from the service data) may be compared and unmet needs for services identified.
- In those countries which do not use a common framework for disability statistics, the aggregation (or disaggregation) of data is not possible due to the different disability definitions or because 'indicators' may not be compatible;

A currently less-well-developed method of identifying problem areas is by gathering information on the interaction of the person with the environment as per the ICF model. For example, if population surveys seek information on environmental barriers to education, the main problem areas across the population could be identified. This could include factors such as public transport, policies, or attitudes from the teachers or students. These factors, once identified, may then be the subject of concerted action by governments and the community at large.

7.4 Can the ICF help in the policy development process?

ICF can serve as a unifying framework, an overall conceptual model, and as a technical resource for the analysis of policy options and for developing models to predict the likely impact of these options. In this way, the ICF facilitates comparability between different policy options with regard to policy coverage, aims, instruments, strategies, responsibilities and financing mechanisms.

*ICF facilitates analysis
of policy options
using a neutral, common
language.*

The ICF uses neutral language and recognises that anyone may have difficulty functioning in some area of life, at any given time and to a variable degree, and is not based on fixed groupings of disabilities. This enables policy makers to clarify potential impacts of policies under development and to create administrative 'classes of disability' or target groups. For example, many income support schemes may focus on the difficulty an individual might have when participating in employment, without investigating the environmental factors which might enable more successful participation in this area of life.

Final selection from different policy options should be influenced by alignment with the Convention on the Rights of Persons with Disabilities. The ICF can help develop non-discriminatory policies:

- ICF is aetiologically neutral and focuses on functioning and the extent of difficulty an individual has, rather than their health condition. With this approach, policies relating to providing support services are more likely to be framed directly in terms of support needs, rather than on less relevant factors, such as whether the individual has been given a diagnosis of a spinal cord injury or of multiple sclerosis. In another example, a focus on autism as the sole criterion for support services discriminates against individuals with other health conditions who may have equal needs. The ICF focus on functioning helps avoid such problems.
- Based on its inclusive view of disability, – focussing on all areas of activities and participation enjoyed by the whole population – the ICF can support identification of areas where individuals with disability have different experiences and outcomes compared to others. This enables identification of gaps in overall policies and programs.

Box 19: World Bank Inaugural Disability and Development Core Course

In 2012, the World Bank conducted a Disability and Development Core Course to increase knowledge of policy makers related to disability, the social and economic relevance of developing policies and programmes responsive to the needs of persons with disabilities, and to include disability into development overall and at the level of sectorial policies and programs.

The course was built on the World Report on Disability (World Health Organization & World Bank, 2011) and used ICF as a conceptual model, framework and classification. It covered six interrelated and complementary themes:

- Disability: Concept, Evolution, Definitions, and Measurement;
- Social and Economic Status of Persons with Disabilities;
- Investment in Human Capital: Education, Health, and Rehabilitation;
- Labour Market Participation of Persons with Disabilities;
- Social Protection: Social Safety Nets and Social Insurance;
- Enabling Environment: Universal Accessibility, Attitudes, Legislative and Institutional Environment, Physical Infrastructure, Transport, and Information and Communication Technologies (ICT).

The principal audience of the course included technical staff from the World Bank and government counterparts in the Bank client countries. The course was also attended by participants from international organisations and donor agencies.

7.5 How can the ICF assist planning at systems level?

In many countries, service systems use contradictory definitions rooted in different disability paradigms. For example, viewing disability as solely based on the diagnosis of a health condition is common, despite the knowledge that disability is influenced by environmental factors. Definitions of disability that are equated with “unable to work” are themselves barriers to inclusive policies and practices. ICF supports movement from a static to a dynamic view of disability (OECD 2003) and adjusts the principles that regulate access to services by setting thresholds accordingly.

ICF supports movement from a static to a dynamic view of disability. The definition of disability provided by ICF facilitates an integrated approach.

To address the needs of persons with functioning problems is a societal responsibility. The definition of disability provided by ICF facilitates an integrated approach. Universal design promoted by the Convention on the Rights of Persons with Disabilities requires states to design their products, environments, programmes and services to be usable by all people. At the same time, states are required to organise, strengthen and extend specialised services particularly in the areas of health, employment, education and social services. Therefore, service planning at the systems level in accordance with the Convention on the Rights of Persons with Disabilities should focus on the overall functioning of the population in accordance with policy priorities and goals. Using such an approach may balance the distribution of resources, strengthening service systems available to everyone while designing specialised services for specific target groups.

The ICF provides a framework to integrate information on environmental factors, the overall functioning of a population, and information on specific subpopulations with certain types of diseases or impairments. This is useful when estimating the gap between the current situation and the desired future. Effective service systems require cross-sectorial coordination, especially to address broad challenges such as poverty and social exclusion. Policy priorities and goals can be communicated across sectors using ICF-based language to target life domains and define minimal levels of participation to be ensured.

7.6 How can the ICF facilitate policy implementation?

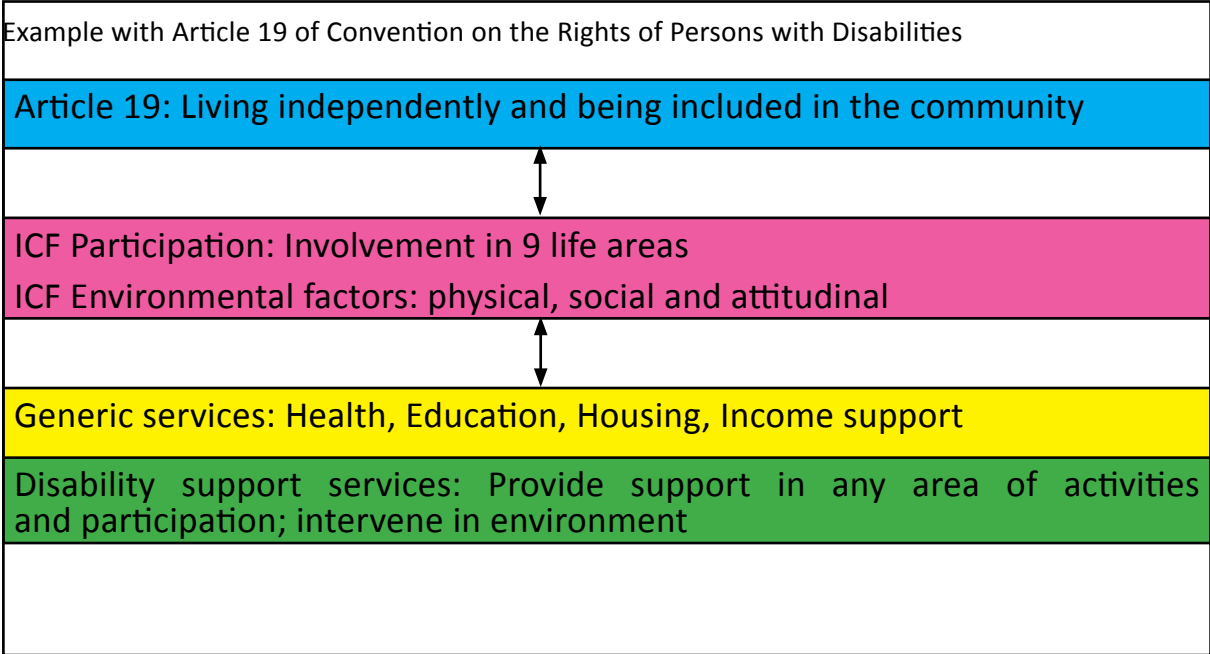
Policies are important environmental factors that influence the lives and well-being of individuals. When implementing policies, the ICF can serve as a technical tool to support cross-sectorial integration of services. In doing so, ICF may also be used to assist with implementation of the Convention on the Rights of Persons with Disabilities. Box 20 illustrates this connection in relation to Article 19 of the Convention. ICF components support a whole-government view that is also person-centred, focusing on the participation of an individual in all areas of life as well as on their environment.

The ICF framework can be used to highlight the effects of the environment on activities and participation, enabling required changes in services and policies to be identified..

Successful cross-sectorial policy implementation is informed by all potential contextual impacts, is supported by commitment from all involved parties, relies on the capacity of targeted services and systems to change, and collaborates with key partners. In this manner, ICF can become an important tool to assess the context, support capacity building, and ensure effective communication.

The ICF has been proposed as an operational tool for international development with ‘the potential to guide disability mainstreaming in international development’ (Vanleit 2008). The ICF framework can underpin a broader framework highlighting the effects of the environment on activities and participation, thus enabling required changes in services and policy to be identified.

Box 20: Using the ICF to link CRPD, policy and services



7.7 Can the ICF help evaluate and monitor the effects of policies?

The ICF can be used in the formulation of policy goals and targets and as a framework to integrate information from various data sources to create a system of indicators. The ICF is a scientific and rights-based instrument that can help build bridges between data and indicators as well as between scientific values and the political and social values expressed in the rights of the Convention on the Rights of Persons with Disabilities (Bickenbach 2011).

The ICF provides key components of database infrastructure for information systems which support program management, monitoring, and evaluation.

The ICF as a classification is intended to provide building blocks for information. As a global standard, ICF provides key database infrastructure for information systems to support program management, monitoring and evaluation. In this way, data collected by service providers can be linked back to policy goals and targets. Box 21 demonstrates a matrix to analyse the functioning of education, health, or social systems which was used as a framework to develop indicators for participation.

Box 21: Matrix to analyse the functioning of education, health or social systems						
	<i>Chronological Perspective</i>					
		Situation/ input	Assessment/ Analysing	Assignment/ Planning	Intervention/ Acting	Evaluation/ Outcome
<i>Systems Perspective</i>	Policies					
	Systems					
	Services					
Functioning and Disability of Person						
<p>The matrix was developed in the MHADIE project (Measuring Health and Disability in Europe, 6th Framework Programme) to analyse disability definitions and concepts used in education systems, for establishing eligibility, for making policy recommendations for inclusive education, for individual educational planning, or for the evaluation of services. Subsequently it was used as a framework to develop indicators for participation.</p> <p><i>Hollenweger J 2010; European Agency for Development in Special Needs Education, 2011.</i></p>						

8 Using the ICF for advocacy and empowerment purposes

8.1 Can ICF be used for advocacy?

ICF is useful for advocacy work by and on behalf of people with a range of functioning problems or disabilities, including problems related to chronic diseases and aging, or of persons in long-term care.

The ICF provides a framework to focus on the situation of the individual rather than specific services and sectors. This makes ICF useful in highlighting overall needs or rights violations. It moves beyond impairment-based groupings of individuals and is a framework to develop advocacy strategies through political activities, litigation or by raising public awareness. As such, ICF is able to bring together different groups under a unified approach to advocate for the rights of individuals with functioning problems.

Using the ICF supports a shift away from a 'charity' model to a rights based model to support advocacy.

The Convention on the Rights of Persons with Disabilities is a human rights instrument and an international normative framework reaffirming and exemplifying that all categories of rights and fundamental freedoms also apply to persons with disabilities. In line with the UN Convention's view of disability, the ICF has a broad scope and requires accounting for environmental factors that influence functioning together with the other factors.

Therefore, the ICF is a potentially powerful tool for evidence-based advocacy. Evidence of discrimination and environmental barriers can be collected across impairment groups and life situations to make the argument for social change or provision of accessible services. Using the ICF supports a shift away from a "charity model" to a "human rights model" of advocacy. The language used for advocacy is an indicator of, and a medium for conveying, values and attitudes. Advocacy activities should focus on promoting participation and not on seeking charity or promoting pity for individuals with disabilities. The ICF framework and model can help to re-conceptualise philosophies of private organisations lobbying on behalf of persons with disability to be in line with a rights-based approach. Donor organisations should assist organisations of persons with disability to build capacity so that all individuals can live with dignity and actively contribute to the development of their society.

The ICF can similarly help highlight the situation of persons with disability within broader policy issues like poverty, gender discrimination or unemployment and illustrate the effects of public policies on people with disabilities and the need for a broader approach to reforms. The World Report on Disability (WHO, World Bank 2011) is a good example of a comprehensive and broad approach taken to disability that, since publication, has been quoted widely, also by organisations of persons with disabilities.

The ICF provides a common language for discussions among disability activists, policy makers, health professionals and the broader public to point out issues of importance across all domains of life. Disability activists can use the ICF to identify and communicate barriers created by services, systems and policies as well as discrimination resulting from practices associated with them. The ICF can also open the way to broaden discussions and to 'get on the same page' with people who habitually use technical language, e.g. medical practitioners and to challenge them to think more broadly about health. Using the ICF as a common language also facilitates networking across countries or linguistic regions.

8.2 Can the ICF be used to measure attitudes and attitude changes?

Chapter 4 of the environmental factors in ICF focuses on attitudes that individuals with disabilities encounter at all levels of society. It provides a map to explore attitudes as experienced by individuals with disabilities in different life domains, and to identify and measure positive and negative attitudes, social norms, and practices or ideologies. Furthermore, ICF can facilitate the development of tools to report experiences of discrimination. In surveys, the ICF can be used to capture beliefs and attitudes related to disability in the general population. An example of this is whether disability is viewed merely as a disorder, or as impairment, or whether it is understood as the result of an interaction between environment and health condition. In combination with measurements of other environmental factors, including available and accessible services or support and how they impact on participation, ICF can help map discrimination as well as attitudinal changes.

ICF can be used to help capture beliefs and attitudes related to disability in the general population.

8.3 Can the ICF support empowerment and independent living?

Participation reflects functioning from the perspective of the individual in society and therefore provides a useful construct to support the process of empowerment. The ICF can be used to develop a rights-driven approach and to create indicators of participation in all life domains or policy areas which support the process of empowerment. The ICF helps to focus on areas of participation that are vital for independent living, such as looking after one's own health or safety, while also illustrating that disability is not directly linked to a specific health condition. For example, needs for health care exist irrespective of impairments or activity limitations. There is increasing recognition that people with intellectual disabilities become disempowered when health professionals 'see the disability' rather than the person.

ICF helps to focus on areas of participation that are vital for independent living.

To facilitate empowerment and independent living, the ICF allows identifying environmental barriers and can highlight the need for adaptations in the current environment. Further, ICF can be very helpful in prioritising services according to the needs and preferences of the individual, and bring the individual into focus, rather than any professional preferences or organisational requirements. It can also help to develop personalised disability support plans and can be used as a tool to communicate with personal assistants. Finally, ICF can help to develop a person-centred approach to health services and to services related to participation in education, employment or community engagement.

Box 22: Using ICF for a patient education programme

At the Ludwig Maximilians-Universität München, an ICF-based patient education programme was developed using the following five steps:

- (1) Definition of relevant areas of functioning,
- (2) Development of strategies to enhance self-efficacy in these areas,
- (3) Development of material and instructions,
- (4) Definition of modules and goal setting; and
- (5) Performance of a pilot test targeting acceptability and feasibility of the program.

The training is carried out in groups of 4 individuals, with five sessions lasting 60 minutes, each, spread over five days. Module 1 targets increasing understanding by the individual of their current level of functioning. Module 2 targets identification of concrete problems and corresponding solutions regarding limited areas. Module 3 is a refresher session for modules 1 and 2.

Feasibility and acceptability of this intervention were verified and a final version of the patient education program was developed. Eleven stroke patients were enrolled in the pilot test. The intervention was well accepted by the participants. The effectiveness of the program will be evaluated in a randomized controlled trial. Due to the universality of ICF and the availability of ICF tools, it is possible to adapt the intervention to different chronic conditions.

Neubert et al 2011

8.4 Can the ICF be used for peer counselling?

The ICF can be used as a training tool for and by peer counsellors to highlight the domains of life where individuals with disability may encounter difficulties or might be in need of advice from a peer. It can also help the individual seeking counsel to express themselves while clarifying the issues at hand. Learning to use the ICF can also be a powerful tool for self-empowerment, as it not only helps one to express oneself, but also facilitates more effective communication with and between professionals, while conveying needs and desires in everyday situations.

The ICF can help illustrate aspects of the life stories of individuals, and how their experiences were influenced by environmental factors, such as support, attitudes or services. It can be a framework in which to consider, understand and work through difficult experiences in order to gain personal strength and meaning in life.

ICF can be used as a training tool for and by peer counsellors to highlight the domains of life where individuals with disability hold the same rights as others and may encounter difficulties or might be in need of advice from a peer.

Box 23: A woman with depression illustrates her own story with ICF

"I have been attending a mental clinic for 10 years since my twenties. Today I have a control somehow and maintain fulltime job.

My HEALTH CONDITION is the depression itself and big weight gain due to the side effect of medicine. My BODY FUNCTION AND STRUCTURE is depressed feeling. Very bothersome and tough, creating big influence to my day to day life.

My ACTIVITY seems fine. I am performing tasks in my job in an acceptable level. I am not a burden to my colleagues, I hope. My PARTICIPATION is maintaining my occupation. I hope to attend "after five" activities with my colleagues and friends, and some volunteer activities, but cannot, as I have to take a rest. I cannot enjoy social participation now.

My ENVIRONMENT is good – understanding and support by boss, colleagues and friends. I am allowed to remain in this post, avoiding moving to a hard post.

I hope to enjoy my life, but cannot. I hope to recover from depression. I know that my HEALTH CONDITION is not easily changed. But ENVIRONMENT can be changed by people's cooperation. I hope present facilitating ENVIRONMENT (attitudes of people around and health care service) could continue."

Sato & Ozawa2010

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World Health Organization Family of International Classifications (WHO-FIC)

Meeting papers and information: <http://www.who.int/classifications/network/meetings/en/>

Posters from the 2012 and 2011 annual meetings, illustrating applications of the ICF around the world, can be found at:

<http://www.who.int/classifications/network/meeting2012/en/index.html>

<http://www.who.int/classifications/network/meeting2011/en/index.html>

Annex 1: List of Acronyms

A&P	Activities & Participation
APA	American Psychological Association
CASP	Child and Adolescent Scale of Participation
CRPD	Convention on the Rights of Persons with Disabilities
EF	Environmental Factors
FIM	Functional Independence Measure
FDRG	Functioning and Disability Reference Group
FRG	Function Related Groups
ICD-10	International Classification of Diseases - 10 th revision
ICF	International Classification of Functioning, Disability and Health
OECD	Organisation for Economic Co-operation and Development
PEDI	Pediatric Evaluation of Disability Inventory
PEM-CY	Participation and Environment Measure for Children' and Youth
UN	United Nations
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
WG	Washington Group on Disability Statistics
WHO	World Health Organization
WHO-FIC	WHO Family of International Classifications
WHO CC	WHO Collaborating Centre for health classifications
WHODAS	WHO Disability Assessment Schedule

Annex 2: List of Boxes

- Box 1: The ICF Model: Interaction between ICF components.....5
- Box 2: Definitions.....5
- Box 3: Example of definition with inclusion and exclusion statements6
- Box 4: Ethical guidelines for the use of ICF 10
- Box 5: Ontological Model of the ICF..... 14
- Box 6: The generic qualifier and an example of an ICF-code 17
- Box 7: Structure of ICF 18
- Box 8: Information systems learn to speak ICF: the FABER solution.....27
- Box 9: Using the ICF to improve rehabilitation outcomes, Western Cape, South Africa.....45
- Box 10: National support services data based on the ICF47
- Box 11: ICF use in threshold setting and eligibility49
- Box 12: ICF utility for monitoring community-based services52
- Box 13: Defining severity and thresholds in population data - a survey ‘link’ to ICF
qualifiers58
- Box 14: Defining severity and choosing a cut-off55
- Box 15: National Disability Survey (NDS) in Ireland.....59
- Box 16: WHODAS 2.0 use.....62
- Box 17: ICF-based Standardised Eligibility Procedure71
- Box 18: ICF in Asia and the Pacific.....76
- Box 19: World Bank Inaugural Disability and Development Core Course80
- Box 20: Using the ICF to link CRPD, policy and services64
- Box 21: Matrix to analyse the functioning of education, health or social systems.....83
- Box 22: Using ICF for a patient education programme.....86
- Box 23: A woman with depression illustrates her own story with ICF.....87

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